

FROM THE EDITOR - Margaret McMillan, BA, MCurrSt(Hons), DipNEd, PhD, FCN, FCNA, RN, GradCertMgt, and Jane Conway, RN, BHSc, BNurs (Hons1), GradCertHRM, GradDipFET, MEd.

EXPLORING NURSING LEADERSHIP

Let me introduce Jane Conway, a colleague who has agreed to be the Associate Editor for *AJAN*. She and I have worked together on online developments in nursing education and practice. Her information literacy will be invaluable as we develop online initiatives for this journal. We have also worked together on projects centering on change and leadership in nursing. We would like to share some of our thoughts about these concepts with readers of *AJAN*.

Three major influences have framed how leadership in Western nursing has developed. These are: the emergence of nursing as a discrete area of professional practice; the influence of feminism on nursing; and, the commitment to providing evidence based practice across the health care sector. These three factors have aligned to produce a climate in which leadership in nursing is now a concept that is recognised as having some meaning. However, how nurses manage the context to ensure that leadership in nursing maintains its relevance requires that leadership occur across the profession at a multitude of levels.

We believe that nursing leaders are those who cause us to rethink the concepts we have of what it means to nurse, to research, to educate and to manage and consider how we enact nursing roles. Therefore, all nurses who engage in thinking about nursing have the potential to participate in synergistic leadership in the profession.

While it has been suggested that nurses must humanise themselves before they can fulfil the goals espoused by the profession and humanise the caring they provide (Rushton, 1991), this is as applicable to nurses' care of each other as it is to care of the patient. Developing a culture in which there is consistent philosophy, shared professional values, effective communication and support requires effective leadership.

Nurses' experience of job related stress is most strongly related to interpersonal relationships with fellow nurses. Other health care workers have only minimal impact on nurses' stress levels and nurses must seriously examine their own behaviour before laying blame for stress at others' doors (Isenalumhe 2000). Manifestations of job related stress are feelings of depression, helplessness, hopelessness and entrapment.

There is increased professional accountability and legal liability for nurses as team leaders. However, despite the belief that the employer should have an interest in professional role development of team leaders and charge nurses in a cost-containment oriented management world, there is little formal training or support for role

development. Perhaps the single most significant factor shaping the culture is the lack of a shared set of values and beliefs about practice among nursing staff. Lack of role clarity manifests itself in division and conflict among groups of nurses. It could be suggested that if the roles of nurses are not clearly defined then there is difficulty in differentiating between them, or justifying position, title and associated remuneration.

It will be nursing leadership that promotes the change of culture to maximise the outcomes from any chosen management strategy. Some staff are required to demonstrate leadership in their position descriptions. However, nursing staff do not articulate what leadership means to them, even though they are able to recognise and comment upon a lack of leadership.

While there are examples of discontinuous change on a global scale (for example World Wars, feminism, and access to the Internet), there are pockets of the community who envision and conceptualise potential change. However, what makes change discontinuous is not that it occurs, it is the consequences of the change and the necessary rethinking of relationships and responses that results.

Perhaps it is discontinuous change itself that facilitates the emergence of leaders as we seek to explain what is occurring and develop strategies to respond to such change. We seek what Weick (1995) would argue is 'sensemaking'. As Dixon (1999, p.17) observes: 'maintaining a sense of stability in unstable environments is the mantra of 21st Century leadership'.

There is sufficient evidence in nursing literature to support the belief that leadership (or lack of nursing leadership) is one of the most widely discussed issues in contemporary nursing. However, the terms leadership and management seem to be used rather interchangeably and are often assumed to equate with position and status. Retention of highly qualified nursing staff should be a goal of any health care organisation. Therefore staff satisfaction should be seen as a priority of the organisation as dissatisfaction with work life seems endemic in nursing.

While nurses may manage (and even lead) within their organisation, unless nurses can maintain momentum for directing the broader organisational and social context, any change they direct may be unsustainable. Thus, there is a need for leading nurses to position themselves as leaders beyond the confines of a single work unit.

In our view, leaders in nursing will facilitate the construction of meaning about what concepts such as

quality nursing care mean for nursing practice: they in fact re-image the identity of nursing in a world of discontinuous change. This will mean that nursing leaders will move nurses from the present comfort zone of victimhood toward emancipation.

In our view, leadership is about directing change, managing is about existing and surviving in changed conditions. Each of us manage to some extent within a given paradigm at any point in time. Probably, few of us lead between paradigms. Identification of those who have this capacity and can encourage others to 'talk the walk' (Weick 1995) may be one of the key strategies for initiating the transformation from leading nurses to nursing leaders.

If, as is widely claimed, nurses have several different ways of knowing (Berragan 1998), then it may well be that there are several different ways of leading. Thus, all nurses have the capacity to become leaders through becoming and being empowered, ie thinking and acting critically about nursing regardless of the level of the hierarchy in which they are positioned. However, the harnessing of this critical thought into directed critical action may be the role of the leading manager who can refashion identity and inter and intraprofessional relationships within a context of rapid discontinuity. If discontinuity results in fragmentation of what is known and results in the need to make new sense of existing relationships, how we make

sense is through directed thinking (ie leading) and how we enact the sense we make is through managing. We doubt that the two are not mutually exclusive.

Mumford et al (2000a) suggest leadership should be framed in terms of capabilities, knowledge and skills rather than specific behaviours. What is needed in nursing more generally is a person who can motivate and inspire individuals, challenge process, facilitate the co-creation of a shared identity for nurses, demonstrate a willingness to take risks, model the way and, to quote Kouzes and Posner (1997), 'encourage the heart'.

We hope that *AJAN* continues to be a journal that is a mechanism for showcasing leadership within nursing and encourages others to assume leadership roles in the context of their practice.

REFERENCES

- Dixon, D. 1999. Achieving results through transformational leadership. *Journal of Nursing Administration*, 29(12):17-21.
- Isenalumhe, A. 2000. Nurses are not their sisters' keepers. *Journal of Nursing Administration*, 30(2):52,58.
- Kouzes, J. and Posner, B. 1997. *The leadership challenge*. Jossey Bass. San Francisco.
- Mumford, M., Zaccaro, S.J., Connelly, M.S. and Marks, M.A. 2000b. Leadership skills for a changing world. *Leadership Quarterly*, 11(1):11-36.
- Rushton, C. 1991. Humanism in critical care: A blueprint for change. *Pediatric Nursing*, 17:399-402.
- Weick, K.E. 1995. *Sensemaking in organizations*. Sage. Thousand Oaks.
-

GUEST EDITORIAL - Barbara Vaughan, MSc, RGN, DANS, RNT.

Barbara Vaughan is Director, Integrated Healthcare Consulting and Visiting Professor, University of Bournemouth, UK

INTO THE TWENTY-FIRST CENTURY - WHAT FUTURE FOR NURSING?

The last decade brought with it a huge explosion in knowledge and understanding of the sciences related to health care. Such an increase gives us the opportunity to tackle disease, restore health and maintain life in ways which had not previously been thought possible. However, as is so often the case, the gain has brought with it new and complex challenges for both recipients and professionals working in health care. Moral dilemmas are faced about the right to die as well as the right to live; what could be achieved through genetic engineering is both positive (combating genetic disorders) and terrifying (a brave new world of cloned beings); costs outweigh resources as both overt and covert rationing enter health care; and, new patterns of disease and infection are challenging and defying traditional solutions.

Within this context it must be argued that the structure in which health care is offered and the roles which the different occupational groups play must be adjusted to meet current need. The dominance of a medical model of health, centrally based in a hospital setting with diagnosis and treatment of disease at its core, can no longer hold true in times when the moral and social consequences of health related problems require equal attention. Furthermore, the reductionist manner in which both services and roles have evolved must be addressed if seamless person centred care is to be achieved.

There is no doubt that there has already been a silent revolution to address these issues which is slowly coming into the public arena and gaining recognition. In a recent study of the emergence of new roles to meet changing demands in health care, three patterns of development were seen for both nurses and professions applied to medicine (Read et al 1999). These were *complementary* roles where occupants adapted part of their function and developed new skills according to patient or service need; *substitution* roles where part of another's role was taken on, usually that of a junior doctor, often at the cost of the original identity of the occupant; and, *niche roles* which were developed to fill a perceived gap in service provision (Scholes and Vaughan 2002).

While there is room for all these approaches to role development, and none should be decried, it is maybe the complementary roles which are offering the greatest opportunity for both nurses and others working in health

care. Ways are being found to shift the boundaries between both disciplines and agencies to prevent duplication of effort and thus make better use of limited resources. More importantly, services which are sensitive to patient's needs rather than divided by occupational domains are starting to emerge. Illustrations can be found with the emergence of intermediate care services to reduce the need for hospital admission or facilitate recovery or recuperation from a home base (DoH 2001). These services abound with examples where teams have overcome the defensive barriers of their occupational roles to share learning and development and working in a truly interdisciplinary way rather than the more customary multidisciplinary approach (Vaughan and Lathlean 1999). It must, however, be stressed that as new ways are found of working together and offering more flexible services it is critical that time and effort are put into development and change is managed in a skilled and open fashion. From the role based work outlined above there is evidence that this is not always the case and care must be taken, most importantly, to ensure patient safety, but also with issues such as equity of access, professional accountability, lines of responsibility and authority, role descriptions and opportunities for research and evaluation (Levenson and Vaughan 1999).

The times which lie ahead for nurses and nursing are both exciting and challenging. While some will present with all the traditional factors which resist change, defend boundaries and hold on to old order ways, for those who are brave enough to dismantle old barriers and seek new relationships with both patients and professional colleagues from other occupational groups the future could be truly good.

REFERENCES

- England. Department of Health 2001 *Intermediate Care - Health and Local Authority Circular*. 19 January 2001. DoH. UK.
- Levenson, R. and Vaughan, B. 1999. *Developing new roles in practice: An evidence based guide*. School of health and related research (SchARR). University of Sheffield. UK.
- Read, S. 1999. Exploring new roles in practice: Implications of developments within the clinical team (ENRiP). *Executive Summary*. School of Health and Related Research (SchARR). University of Sheffield. UK.
- Scholes, J. and Vaughan, B. 2002. Cross boundary working: Implications for the multiprofessional team. *Journal of Clinical Nursing*. 11(3): (In press).
- Vaughan, B. and Lathlean, J. 1999. *Intermediate Care: Models in Practice*. London. King's Fund. UK.

THE EXPERIENCES OF ADULTS WITH CEREBRAL PALSY DURING PERIODS OF HOSPITALISATION

Amanda Buzio, RN, GradDipClinTeach, Post Basic Neuroscience Certificate, is a Professional Development Advisor at The Spastic Centre of New South Wales, Australia

John Morgan, Consumer Liaison Officer (Retired), The Spastic Centre of New South Wales, Australia

Diane Blount, The Spastic Centre of New South Wales, Australia

ACKNOWLEDGEMENTS

This project was supported by a seeding grant from the Research Centre for Adaptation in Health and Illness, a collaborative research centre between the University of Sydney and the Central Sydney Area Health Service.

The researchers gratefully acknowledge the advice and support provided by Karen Willey, Research Consultant, Research Centre for Adaptation in Health and Illness.

Accepted for publication April 2002

Key words: cerebral palsy, disability, hospitalisation, experience

ABSTRACT

People with cerebral palsy may have a range of disabilities that can result in daily dependence on others to meet some or all of their basic and more complex care needs. The aim of this New South Wales research was to examine the experiences of adults with cerebral palsy during inpatient admission to a number of public hospitals. A self-selected sample of 31 adults with cerebral palsy completed a questionnaire that collected information related to their disability-specific needs and how well these were addressed by nursing staff during admissions to hospitals. Analysis of the data revealed that many respondents felt hospital staff had limited knowledge and skills of caring for people with cerebral palsy, resulting in their basic care needs not being adequately addressed during periods of hospitalisation. Changes in nursing assessment, continuing education and discharge planning are recommended to address these issues.

INTRODUCTION

When a patient enters the public hospital system, it is generally acknowledged that responsibility for providing holistic care that meets the patient's individual needs remains with the hospital. However, people with disabilities often have disability-specific care needs necessitating assistance from a carer or family member on a daily basis. When these people enter the hospital system, it is perhaps unclear who is responsible for meeting these needs as there may be no clear guidelines for hospital staff to specifically address these issues.

Anecdotal evidence from clients of The Spastic Centre of New South Wales, Australia, with cerebral palsy or similar disabilities, suggested that staff in NSW public hospitals lacked knowledge and experience when caring for people with disabilities, particularly those with severe disabilities who have no verbal communication. Specifically, the issues raised by clients and carers included:

- Hospital staff lack of knowledge and skills in caring for patients with cerebral palsy.
- A common lack of pre-admission or admission planning by hospitals for the disability-specific needs of the patient and the extra workload involved in his/her care.
- Inadequate discharge planning which often did not investigate current at home support services or assumed that existing support services would be adequate to care for the patient post-discharge, regardless of the change in care needs.

These factors were reported as often resulting in communication difficulties between patients and hospital staff, lack of understanding of the patient's physical limitations, inability of hospital staff to meet the nutritional and hygiene needs of the patient and confusion over the ongoing care requirements of the patient after discharge.

Cerebral palsy is defined as a group of non-progressive, but not unchanging, disorders of movement relating to

damage to, or lack of development of, the developing brain (Mutch et al 1992). Along with its many associated conditions it often reflects a variety of disabilities, including physical, sensory and intellectual, and in this way may be considered representative of a wide range of disabilities. Many adults with cerebral palsy now live in the community independently or are supported by paid carers or family members with their daily care needs.

LITERATURE REVIEW

A search of the literature revealed a number of published articles dealing directly with hospital care of people with disabilities. A survey of the experiences of patients with physical disabilities and nurses in acute hospital wards in England (Atkinson and Sklaroff 1987) revealed that many nurses felt they had inadequate training and experience to care for patients with disabilities in this setting. This study also showed that improvement in communication between nurses and patients would facilitate the nursing assessment of patients with disabilities during admission to the ward. Dewing (1991) states that nurses in acute-care settings may be unaware of the special needs of patients with physical disabilities. She argues that initial assessment of their special needs and preparation for discharge are essential components of the nursing care plan if nurses are to start the process of meeting their needs in the acute care setting.

According to a survey by Thomas (1999), people with a disability report barriers to health care which include limited physical access to hospitals and inappropriate staff attitudes and behaviours towards them. Health professionals' misconceptions about disability may lead to further disablement and a failure to accommodate the person's individual needs. Scullion (1999) noted that some people with disabilities are dissatisfied with their contact with health care professionals. Personal accounts and research support the opinion that health professionals may consider the needs of people with disabilities of lower priority compared with those of able-bodied patients, resulting in this group receiving a lesser quality nursing service than other people.

A report by Royal Melbourne Hospital on nursing children with disabilities in an orthopaedic acute care hospital setting in Victoria (Robinson et al 1993) identified that the needs of children with disabilities and their families were not being met during periods of hospitalisation. It was noted that children with disabilities were surrounded by health professionals whose primary focus was the technical and medical aspects of their management. During their hospital stay, these children required skilled and informed nursing care which focused equally on orthopaedics and disability. However, the authors felt that this was rarely achieved. Inadequate information about the basic needs of the child, their habits and routines, was obtained on admission to the ward and nursing hand-overs failed to include information about the child's disability-specific needs. This resulted in nurses facing great challenges when trying to provide basic

nursing care, often resulting in inappropriate and inadequate care (Robinson et al 1993).

A number of studies examining the general health care of people with disabilities refer to the problems that they face when accessing health services in general. In a study of residents with intellectual disabilities in Sydney, Beange (1996) identified that this minority population received substandard community health care. Adults with intellectual and other disabilities frequently suffer medical problems that remain undiagnosed, primarily because of lack of familiarity with and knowledge of disability specific health issues by health practitioners (Cathels and Reddihough 1993; Beange 1996; Lennox et al 1997; 1998). In their study of the current health status of adults with cerebral palsy, Balandin and Morgan (1997) received a number of responses detailing a lack of faith and even disgust in the medical profession because, in some instances, it was felt that doctors had no knowledge of cerebral palsy.

Information related to the current state of general care provided by hospitals in Sydney reveals that people with disabilities may not be the only group to experience difficulties obtaining adequate hospital care. People without disabilities who have had recent experiences as patients in public hospitals also report that hospital care is not meeting their needs. Scotford (1999) describes a recent experience in a teaching hospital in Australia as chaotic and distressing, 'dangerous to health and lacking in humanity' (Scotford 1999, p.138). As one of a roomful of bedridden patients, she felt isolated and neglected as the over-stretched and disorganised hospital system failed her in her time of need. This experience included prolonged waiting for call bells to be answered, clumsy and disorganised nursing and a lack of routine in relation to medication, personal care and mealtimes.

Aspinall (1999), in a personal account to the editor, also reflected on a recent hospital stay in a large teaching hospital, citing economics and staffing difficulties as leading to an erosion of patient care. She observed that patients with complex care needs, requiring longer hospital stays, placed stress on the nursing and medical environment and that deterioration in patient care was an important issue, requiring urgent attention. It is a concern that able-bodied people who can speak for themselves report such negative experiences of their stays in hospital, highlighting further the need to explore the impact on people with disabilities, particularly as they often have difficulty communicating.

METHOD

Ethics approval and support for this project was obtained from The Spastic Centre of New South Wales Ethics Committee. As the researchers and participants were employed at and/or clients of The Spastic Centre, the granting body deemed this approval acceptable and no ethics approval was sought from the Research Centre for Adaptation in Health and Illness, The University of

Sydney or the Central Sydney Area Health Service. This project was designed to address the research question - what are the experiences of adults with cerebral palsy during in-patient admission to public hospitals in Sydney?

Data collection

This descriptive study collected data relating to respondents' demographic details and disability specific needs and information about recent experiences in hospital. The 17-item self-administered questionnaire was developed based on the themes and issues arising from the literature and anecdotal information from clients of The Spastic Centre and their carers and families. The questionnaire was produced in a large print, plain English format and it was acknowledged that not all respondents would be capable of writing their answers independently. Instructions for scribes were included at the beginning of the questionnaire to ensure that the respondents' exact responses were documented.

In an attempt to provide an easy format for people with communication disabilities to respond, the questionnaire consisted of a variety of formats. Multiple-choice questions and yes/no responses were used to collect demographic data and information related to disability.

For example:

Who do you live with? (Circle the correct response)

- a) Alone b) Spouse/Partner
c) Family other than spouse d) Other

Five point Likert scales, yes/no responses with room for comments and open-ended questions provided a format for respondents to describe their experiences.

Examples of questions included:

Q. Do you think hospital staff caring for you, were knowledgeable about caring for people with disabilities?

Yes No

Comments _____

Q. How well were your disability-specific needs met by hospital staff?

(Please circle any number 1 to 5, where 1=NEVER and 5=ALWAYS, to indicate your response to each of the following)

a) Mealtime assistance:

1	2	3	4	5
never	almost never	sometimes	almost always	always

Q. How could your disability-specific needs have been better met by hospital staff?

(Write in any ways you think your needs could have been better met)

a) Mealtime assistance:

After a pilot of the questionnaire on four volunteers who met the study criteria, the format and content were evaluated and modified. Modification included re-wording some questions to remove ambiguity, enlarging the print again, adding a question on the issue of physical access to the hospital and changing the format to make it easier to read. The volunteers were re-tested with the modified questionnaire, before commencement of the main study. Results from the second pilot were included in the data analysis.

To be eligible for inclusion in the study, the sample was required to meet the following criteria:

- Aged 20-70 yrs;
- Have cerebral palsy;
- Have had at least one admission, greater than two days, to a public hospital in Sydney in the last two years; and,
- **Have written, informed consent by the person or their 'person responsible' (see *Guardianship Act 1987*).**

The lower age criterion was set as the researchers were aiming to obtain a sample with experiences of general hospitals. It was acknowledged, from contact with the specific client group, that paediatric clients with cerebral palsy and health issues requiring regular hospitalisation, often remained in paediatric settings later than the non-disabled community, ie up to the age of 19 and 20. The upper age limit was agreed on by consensus.

Formal recruitment of respondents commenced in May 1999. The project was advertised through the *DisAbility Now* newsletter, a publication of The Spastic Centre of NSW and through fliers with details of the project and an invitation to join the study which were sent to 39 Spastic Centre services and 27 external disability organisations. A total of 39 respondents were finally recruited.

On contacting the researchers, each respondent was allocated a research number and sent a package containing an information sheet, consent form, questionnaire and a reply-paid envelope. Respondents were asked to return the signed and completed consent form and questionnaire within two to four weeks. They were contacted by telephone one week after being sent a package to answer any questions and encourage a quick response. Non-responders were contacted by phone up to two times.

Data collection continued until July 1999, when 32 completed questionnaires had been received. Of these, one participant stated they did not have cerebral palsy, so was withdrawn from the study. This resulted in a final sample size of 31 respondents.

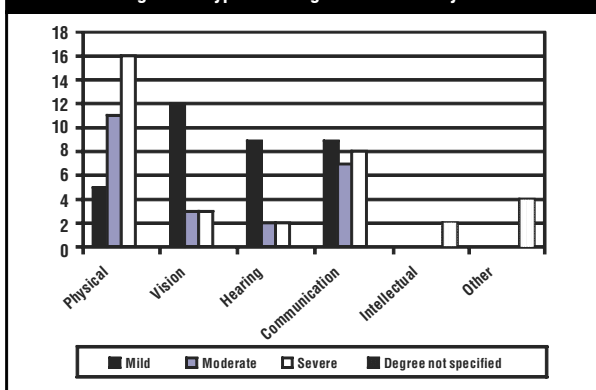
RESULTS

Formal analysis of the data commenced in August 1999, when data collection was complete, using the SPSS statistical analysis program and hand coding of qualitative data. Where appropriate, qualitative data were allocated into positive or negative responses and examined for recurring themes.

1. Demographic data

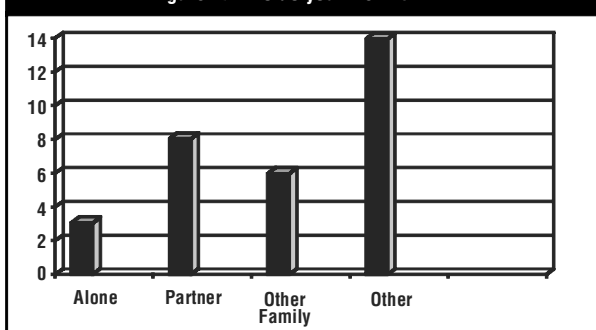
- 58% (18) of respondents were male.
- 97% (30) of respondents were aged 20-59 years, with one respondent aged over 60 years.
- All respondents had cerebral palsy with varying type and degree of disabilities (figure 1). These included physical, visual, hearing, communication and intellectual, as identified in the *Disability Services Act, NSW (1993)*. Respondents' identified their type and degree of disability based on personal knowledge or awareness. Medical diagnosis was not requested. Moderate to severe physical disability was reported by 84% (26) of respondents, with the majority also reporting at least one other type, in particular communication disability, 77% (24).

Figure 1: Type and degree of disability



- 87% (27) reported that they required some level of paid carer assistance on a daily basis, ranging from one to more than six hours per day.
- Level of education, in all cases, was below university level, with only 13% (4) reporting education at a TAFE level.
- Living situations are represented in figure 2. 45% (14) of respondents lived with people other than family and only 10% (3) lived alone.

Figure 2: Who do you live with?



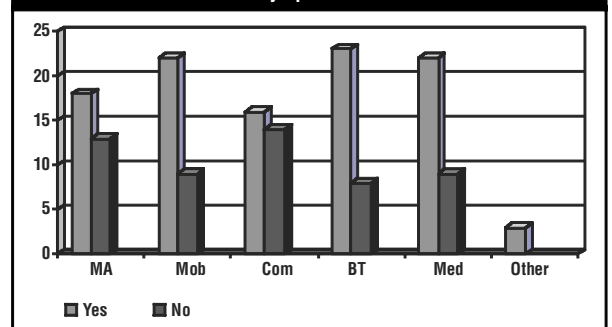
2. Level of care required

Many respondents (n=16) reported multiple admissions to hospital within the previous two years, indicating that the experiences reported were based on two or more admissions. Respondents were asked about their disability specific needs, whether they volunteered this information to staff and whether this information was requested

by hospital staff. Disability-specific needs were classified into six categories; Mealtime Assistance (MA), Mobility Assistance (Mob), Communication (Com), Bathing/Toileting (BT), Medication (Med) and Other (O), indicating that the person had special needs in these areas as a result of their disability. Other reported disabilities included sleep apnoea, epilepsy and multiple disabilities.

On admission to the ward, all respondents reported they volunteered information about at least one of their disability specific needs to hospital staff (figure 3). Many provided information about all needs, particularly those people with communication disabilities, as this information was required before hospital staff would know how to communicate with the person. This information was sometimes conveyed verbally by the individual or their carers but many respondents also reported providing written information of their care needs. However, only 23% (7) of respondents reported being asked by hospital staff for information about their disability-specific needs, as part of the admission process.

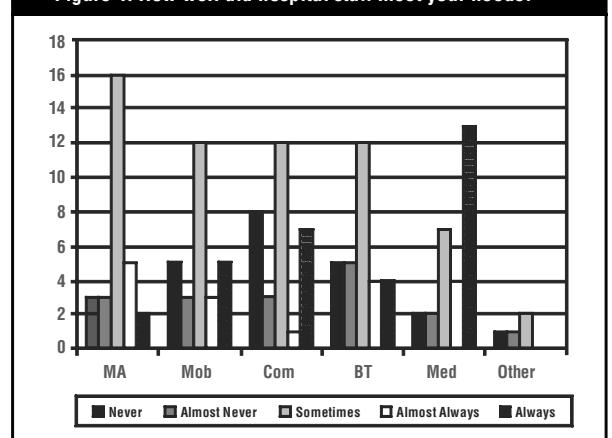
Figure 3: Did you volunteer information about disability-specific needs?



3. Level of care received

Respondents were asked to indicate how well they felt hospital staff met their disability-specific needs during hospitalisation. A 5 point Likert scale was used to obtain the level of response, ranging from 1 (never) to 5 (always). Where no assistance was required, these questions were left blank or marked N/A. Responses indicated that the majority of respondents (>60% in all disability categories except medication) felt these needs were never, almost never or only sometimes met by hospital staff (figure 4).

Figure 4: How well did hospital staff meet your needs?



Some respondents found staff response when called or buzzed unacceptably long often resulting in the person feeling neglected and unimportant. Some respondents felt an inadequate number of staff and staff shortages may have contributed to the care able to be provided. Some respondents stated that their care was often left until paid carers or friends arrived to take over, or that hospital staff only provided assistance if no visitors were present. Two respondents reported having to rely on other patients for assistance with meals.

When asked how hospital staff could have better met these needs, three main themes emerged from the responses:

- increased staff knowledge of cerebral palsy;
- increased skills required to care for people with disabilities; and,
- increased staff patience when caring for people with cerebral palsy.

For example:

Taking time for the person with CP to relay the message they're trying to get across; staff to listen when person with CP tells them the best way to assist.

Not all respondents in the study were unhappy or dissatisfied with the care they received in hospital. For example:

They certainly looked after me; I found the staff...very well advised and I had no problems

13% (4) reported receiving a high standard of care and were very impressed with the facilities and resources available, indicating some staff within the public hospital system are familiar with the care needs of people with cerebral palsy and are competent in providing this care.

4. Staff knowledge

87% (27) of respondents felt that hospital staff had some degree of knowledge and/or skill deficit when caring for people with cerebral palsy. Hospital staff, particularly nurses, were often perceived as ignorant of how to provide appropriate care to a person with cerebral palsy. For example:

They had no/very little idea, were asking house staff all the time; most staff don't know much about cerebral palsy...the condition is a mystery and so are the needs.

As a result of this over 60% (19) of respondents chose to rely on the assistance of either family and friends or paid carers (or both) to provide basic care for them during their hospital stay.

5. Staff attitude

Examination of respondents' perceptions of the attitude of hospital staff towards people with a disability elicited mixed responses. Comments were both positive and negative but some respondents felt that a positive staff attitude did not always result in them receiving quality care during their stay in hospital. For example:

The hospital staff were mostly pleasant but they just didn't have a clue about people with cerebral palsy and they seemed as though they did not want to know either.

6. Communication

Hospital staff were often reported as not having the time or patience to listen to or read specific instructions from the patient or their carers. Respondents who had a communication disability often stated staff needed to allow more time for them to communicate.

There was a positive correlation between people who were unable to communicate verbally and dissatisfaction with the care received. Of the 15 respondents in this group, all reported they were not specifically asked about their disability needs on admission to hospital.

However, all but one provided this information, in writing, to hospital staff anyway. Despite this, all of the respondents who were unable to verbally communicate, reported some degree of difficulty in getting hospital staff to meet their basic needs. All respondents in this group who utilised augmentative communication devices (such as compic symbols or electronic talkers), stated staff did not attempt to utilise these whilst trying to communicate with the patient. These people were therefore restricted to yes/no communication with hospital staff during their entire stay in hospital, remaining dependent on the staff to guess what they were trying to say.

7. Physical environment

Other themes emerged from the responses, including lack of resources and physical restriction of environment. Lack of hoists or appropriate seating meant some respondents were restricted in their mobility, often confined to the bed for their entire stay, even though they were well enough to get up. 35% (11) of respondents indicated they had difficulty physically accessing the hospital environment, mainly due to slippery floors or limited access in bathrooms and bedrooms. This made mobilisation within the hospital environment dangerous or difficult, although one respondent reported having trouble getting into the hospital from the car park.

8. Discharge planning

55% (16) of respondents reported some degree of discharge planning by the hospital prior to discharge. This ranged from asking the person if they would cope at home to arranging community nurse follow up. The remaining 45% (15) of respondents indicated that discharge planning was not discussed with them during their stay. Whilst this was not always seen as an issue, some respondents indicated the hospital had assumed that the carers at home were able to take over care. In some instances, this caused problems for the respondents at the time of discharge or after they had returned home.

DISCUSSION

The results of this study are consistent with the reviewed literature and indicate that some adults with

cerebral palsy have negative experiences when admitted as a patient to a public hospital. People with moderate to severe communication disabilities appear to experience more difficulties than those with milder disabilities in obtaining holistic nursing care as they are often not offered the opportunity to clearly communicate with staff.

The Disability Services Act (DSA) NSW (1993) states that people with disabilities have the right to ensure their specific needs are met. When related to hospital care, this can be interpreted to mean that a person with a disability entering the hospital system is entitled to expect their disability-specific needs will be met as part of the overall service delivery. Some NSW area health services employ disability advisors to advise on general disability issues in an attempt to comply with this *Act*. However, as their role is not in the clinical setting, information may not be provided to staff who are providing direct clinical care. This study suggests the need for increased awareness of cerebral palsy and disability issues amongst clinical staff working in public hospitals to ensure the requirements of the *DSA NSW (1993)* are met.

The *EQulP Guide* (ACHS 1998) contains standards and guidelines for The Australian Council on Healthcare Standards (ACHS) Evaluation and Quality Improvement Program. This document is used to guide all health organisations, including public hospitals, in meeting the requirements of accreditation. Contained within the guide, Standard 2.2 Patient/Consumer Rights, Responsibilities and Ethical Issues, includes 'access to appropriate, equitable care; personal dignity; participation in planning and decisions regarding their care...' (ACHS 1998, p.3). Based on the results of this research, it could be argued that some public hospitals are not properly meeting the requirements of this accreditation standard when providing services to people with disabilities.

It is interesting to note that only a small number of respondents were questioned about their disability during the admission process. Possibly some hospital staff felt embarrassed or awkward addressing these issues so directly. Although not demonstrated by this study, nurses and doctors routinely obtain information about allergies and past medical history when admitting patients to hospital. These issues are clearly seen as impacting on the patient's care and therefore require careful investigation. It is clear that if a person is admitted to hospital for routine surgery but also has a disability, particularly a moderate to severe disability, they will require more support and therefore more nursing hours than a person without a disability admitted for the same procedure. However, if recognition of these greater care needs does not occur on admission, the need for more nursing hours will also not be recognised resulting in inadequate staffing levels. Such inadequate levels of staffing have clearly been identified as a factor influencing patient care (Aspinall 1999; Atkinson and Sklaroff 1987; Robinson et al 1993; Scotford 1999).

While lack of knowledge of cerebral palsy and disability issues may explain the reported inadequate care,

this should not be an issue when specific information is provided to assist hospital staff. It could be argued that the information supplied may be inappropriate or difficult to understand or that hospital staff have insufficient time to read the information. Clearly there is a need for collection and utilisation of concise, standardised documentation of disability-specific needs on admission to hospital.

It is well established that adequate discharge planning results in decreased length of stay and readmission rates (Evans and Hendricks 1993). Chadwick (1998) advocates that discharge planning should begin at initial assessment, should be coordinated between both medical and nursing staff and should include a discharge summary sheet sent home with the patient to ensure follow up instructions are adhered to. This study did not investigate the process of discharge planning implemented by the hospital in any detail. However, it did demonstrate that only half of the respondents reported discharge planning as part of their care. This lack of discharge planning sometimes caused problems for the respondents, and indicates a need to improve the practices within hospitals when caring for people with cerebral palsy.

Gething (1992) reports that health professionals' attitudes can influence the quality of service provided to people with disabilities. In her study of nurses' attitudes toward people with disabilities, Gething observed that nurses in Australia displayed a significantly more positive attitude toward people with disabilities than the general population. Of the 17 respondents in our study, who felt hospital staff had positive attitudes towards people with disabilities, 13 also reported inability of these staff to completely meet their basic care needs, suggesting, in this instance, positive attitudes did not necessarily ensure holistic nursing care.

LIMITATIONS OF THE STUDY

Limitations of the study included the small sample size, the mix of reported disabilities and not eliciting the type of medical discipline, ward or area that the respondents were admitted to. The sample was also self-selective and, therefore, may not be truly representative of the cerebral palsy community. People who had negative experiences in hospitals may have been more motivated to join the study.

The breakdown of disability types reported by respondents indicates that not all disabilities were equally represented in this study. People with intellectual and psychiatric disabilities may have experiences that have not been captured in this study.

During the development of the questionnaire careful consideration was given to asking respondents to identify the hospitals related to their experiences. However, it was considered that this may have been too controversial. Respondents were from different regions across Sydney. Assuming they accessed their local public hospital, the experiences reported should be representative of different hospitals in different areas.

RECOMMENDATIONS

Public hospitals have a responsibility to ensure all patients receive care that meets their individual needs, including disability-specific needs. In so doing, hospitals must acknowledge that increased resources may be required to ensure equality of service for patients with disabilities and higher levels of need.

The nursing admission process should include a comprehensive history with details of any disability-specific care requirements so the need for extra resources is recognised and addressed as soon as the patient enters the system. For patients entering the system as a routine or booked admission, this process could be commenced during pre-admission planning. Once obtained and documented in the patient's file, all relevant staff should be advised to read this information and utilise it when planning and providing care. The time spent researching and reviewing this sort of documentation will often result in time saved when providing clinical care to the patient. This information can also be useful when planning for the patient's discharge to ensure, where necessary, appropriate community services are accessed and continuity of care occurs after the patient leaves the hospital environment.

Continuing education for hospital staff should also include training and support to ensure all staff are aware of the issues for people with disabilities and competent in addressing their care needs. No longer are people with disabilities restricted to disability-specific wards. A variety of different resources are available to educate and skill hospital staff in caring for people with disabilities. The Disability Awareness Package, 2nd Edition (Gething et al 1994) was designed to equip health service providers so that they can provide more appropriate and effective services for clients with a disability. Disability organisations, such as The Spastic Centre of NSW, can also provide information and training to generic services to assist them when providing services to their clients with disabilities. Staff who are responsible for professional development in hospitals are encouraged to utilise these resources and strategies to address the skill and knowledge deficit that is reported in this study. Further research investigating public hospital nursing staff's experiences, perceptions and knowledge of caring for people with cerebral palsy would also be beneficial in clarifying the issues of concern for nurses.

CONCLUSION

This project was undertaken in response to personal reports and anecdotal evidence from clients of The Spastic Centre of NSW and their families and carers. The results support these reports and are consistent with the reviewed literature, indicating that some people with

cerebral palsy do not receive holistic care that meets their disability-specific needs when admitted to public hospitals.

Hospitals are responsible for ensuring all the needs of their patients are met, including those with disabilities. There is a need to improve hospital staff knowledge and skill when caring for people with cerebral palsy. Lack of hands-on resources and poor staffing levels will also impact on the level of care able to be provided. Concise history taking on or before admission to hospital and ensuring on-going utilisation of this information will assist hospital staff when attempting to meet the disability-specific needs of patients with cerebral palsy. Consistent discharge planning will assist in the continuity of this care back into the community. Addressing these issues at the local and area level will assist hospital staff to develop the skills required to provide the holistic care that adults with cerebral palsy deserve.

REFERENCES

- Aspinall, D. 1999. A patient's room with a view. *The Lamp*. Dec/Jan. 56(11):24.
- Atkinson, F.I. and Sklaroff, S.A. 1987. *Acute Hospital Wards and the Disabled Patient*. London: Royal College of Nursing, UK.
- Australia. Department of Health. 1998. *The EQUiP Guide*. Sydney: Australian Council on Healthcare Standards Evaluation and Quality Improvement Program.
- Australia. NSW Government 1993 Disability Services Act. No.3. NSW Government Information Service.
- Balandin, S. and Morgan, J. 1997. Adults with cerebral palsy: What's happening? *Journal of Intellectual & Developmental Disability*. 22(2):109-124.
- Beange, H. 1996. Caring for a vulnerable population. *Medical Journal of Australia*. 164:159-160.
- Cathels, B.A. and Reddihough, D.S. 1993. The health care of young adults with cerebral palsy. *Medical Journal of Australia*. 159:444-446.
- Chadwick, A. 1998. Discharge planning: Are we meeting the needs of our patients? *Australasian Journal of Neuroscience*. 11(4):8-11.
- Dewing, J. 1991. Physically disabled people in acute care. *Nursing Standard*. 5(22):37-39.
- Evans, R.L. and Hendricks, R.D. 1993. Evaluating hospital discharge planning: A randomised critical trial. *Medical Care*. 31(4):358-370.
- Gething, L. 1992. Nurse practitioners' and students' attitudes towards people with disabilities. *The Australian Journal of Advanced Nursing*. 9(3):25-30.
- Gething, L., Cahill, L., James, M., Redmayne, G. and Reynolds, F. 1994. *The Disability Awareness Package: 2nd edition*. Sydney: The University of Sydney.
- Lennox, N., Cook, A. and Diggins, J. 1997. Caring for adults with intellectual disabilities. *Modern Medicine of Australia*. May:79-88.
- Lennox, N.G., Diggins, J.N. and Ugoni, A.M. 1997. Barriers and solutions to the general practice care of people with an intellectual disability. *Journal of Intellectual Disability Research*. 4:380-390.
- Mutch, L.W., Alberman, E., Hagberg, B., Kodama, K. and Perat, M.V. 1992. Cerebral palsy epidemiology: Where are we now and where are we going? *Developmental Medicine and Child Neurology*. 34:547-555.
- Robinson, A., Oxnam, C., Kelly, S., Broadbent, J. and Dillon, M. 1993. A study into nursing children with disabilities in an acute care context: The 3W disability awareness group research report. Melbourne: The Royal Children's Hospital.
- Scotford, N. 1999. Humbug, health and humanity: A patient's tale of care in a public teaching hospital. *Australian Health Review*. 22(4):135-138.
- Scullion, P. 1999. Conceptualising disability in nursing: Some evidence from students and their teachers. *Journal of Advanced Nursing*. 29(3):648-657.
- Thomas, S. 1999. How healthcare professionals can become disability aware. *Nursing Standard*. 13(27):20.

MEASURING THE OUTPUTS OF NURSING RESEARCH AND DEVELOPMENT IN AUSTRALIA: THE RESEARCHERS

Professor Lesley Wilkes, PhD, MHPed, Grad Dip Ed (Nurs), BSc (Hons), RN, CM, Renal Cert, is Professor of Nursing in the Clinical Nursing Unit of the University of Western Sydney, Wentworth Area Health Service, New South Wales, Australia

Associate Professor Sally Borbasi, RN, BEd(Nursing), MA(Educ), PhD, is Associate Professor, School of Nursing and Midwifery, Flinders University of South Australia, Australia

Dr Cathy Hawes, BSc(Hon), MAgSc, PhD, is Director, Research and Education Unit, School of Nursing and Midwifery, Flinders University of South Australia, Australia

M. Stewart, Student, College of Arts, Education and Social Sciences, University of Western Sydney, Australia

D. May, Student, School of Nursing and Midwifery, Flinders University of South Australia, Australia

Accepted for publication September 2001

Key words: Australian, authorship, journals, nursing knowledge, publications, research

ABSTRACT

It is vital for nurses to publish in order to provide evidence of their practice and to increase the knowledge base of their discipline. This paper is one of two that reports on an investigation of the nursing research published by Australian authors from 1995-2000 in 11 nursing journals based in Australia, the UK and the USA. The focus of this article is on the researchers drawn from a total of 509 articles that were content analysed and categorised according to topics of research, paradigm, methods used and funding acknowledgment. The researchers were analysed on the basis of gender, discipline, employment base and location.

Publications had from one to 10 authors, averaging two, with 26 authors claiming 23.6% of research articles. The most common discipline area was nursing and universities were the leading area of employment. Authorship was not limited to capital cities reflecting the spread of university campuses in rural areas. Research papers made up 12.5% of possible articles, supporting the notion that few nurses publish research papers in the refereed general nursing journals we focused on.

INTRODUCTION

The practice of nursing can no longer be ritualised with no rationale for practice provided (Walsh and Ford 1992). Researching nursing effectiveness and using the results of such research in practice is increasingly important as governments and national associations are basing the distribution of limited resources on evidence based care (Chalmers 1993). Knowledge of current research is a precursor of evidence based practice (Wallace et al 1997). Systematic reviews of the literature are one way of providing knowledge of current research as a precursor to evidence based practice. However, systematic reviews require nurses to disseminate their research findings before they can be used to improve clinical practice. We report a study of nursing research published by Australian authors from 1995 to 2000 in 11 nursing journals. While a number of factors were investigated such as the actual topics of the research, the paradigms and methods used, the researchers and sources of funding, this paper will present a profile of the researchers.

LITERATURE REVIEW

The impetus for the current study came from a project conducted in the United Kingdom (UK), *Measuring the Outputs of Nursing Research and Development* (Rafferty et al 2000). This UK study investigated the type of nursing research being published with particular interest in the

topics of research, funding and publication during the period from 1988 to 1995, using the UK Research Outputs Database (ROD). The most prolific geographic areas of publication identified were from authors in the cities of London and Manchester, and only a third of the research appeared to be funded (Rafferty et al 2000; Traynor and Rafferty 2000). Further, the research was extremely diverse with 50 subject areas identified. The leading two in terms of output were mental health (337, 18%) and nurse education (268, 15%). Rafferty et al (2000) suggested topics reflecting clinical care had tended to grow over the period studied.

There is considerable discussion and research in the literature on why nurses should publish and read research, which nurses do or do not read and/or publish research, and, what topics they pursue (Dunn 1991; McConnell and Paech 1994; Hicks 1995; Jackson et al, 1996; Smith 1996). Both government and the profession have emphasised the importance of effective dissemination and implementation of research findings (Mulhall 1996). It has been stated that 'A body of written knowledge is crucial to the establishment of a discipline' (Goody 1977, p.50). Thus, publication is the primary means of communicating research, practice and theory and is essential for the recognition of the individuals within it and of the discipline as a whole.

Published work alone does not constitute a discipline and scholarship. Unpublished work and informal exchange also contribute to the development of knowledge. However, these cannot be widely assessed and critically appraised and neither do they qualify as the 'public knowledge' which is the core of a discipline and its scholarship (Ziman 1968). As well, it can be considered unethical not to publish research results as the projected publication of results is part of the approval of research by ethics committees (Blunt et al 1998). For these reasons it is crucial for nurses to circulate research findings in the quest of scholarship and excellence in practice (Mulhall 1996). As suggested by Styles (1978, p.28) 'not to publish is enacting nothingness in a part of one's professional soul'.

Nurses publish in a range of venues from newspaper articles, reports, conference papers and peer-reviewed articles and books. However, many of the papers and articles in the nursing press are written by a small number of people (Mulhall 1996). Hicks (1992) found that the level of publication of research in the United Kingdom (UK) nursing population was low with only 3% of nurses promulgating their findings in national academic and professional journals. In a later study based on a national survey of 230 nurses in the UK, she discovered that only 10% of the 161 nurses who conducted research submitted it for publication (Hicks 1995). She also found the authors were more likely to be managers than clinicians, be nurses with post basic qualifications and aged between 21-30 years. These findings are interesting, as it has been found that the theses of postgraduate nurses are unlikely ever to be published (Mulhall 1996).

In the same period, in the UK, nursing was the fastest growing of 25 health related fields in the ROD (Rafferty et al 2000; Traynor and Rafferty 2000). In a study on the other side of the Atlantic, Winslow (1996) searched the databases of MEDLINE and CINAHL and found that of 40 abstracts published and presented at the American Association of Critical Care Nurses National Conference in 1989, only 37.5% had been subsequently published as full journal articles by 1995. Data on published and unpublished research conducted by Australian nurses has been compiled by the Royal College of Nursing, Australia (RCNA) in the last decade (RCNA 1998) but a systematic analysis has not been conducted.

A number of studies have examined trends surrounding publication by nurses in Australian refereed journals at different times in history since the late 1980s (Daly 1990; McConnell and Paech, 1994; Jackson et al 1996; Roberts 1997). In his study, Daly (1990) found that research was the least represented area of publication in Volumes 1, 3 and 5 of the *Australian Journal of Advanced Nursing (AJAN)* between 1983 and 1988. McConnell and Paech (1994) compared outputs in Volumes 1-4 and 5-8 of the *AJAN* and found little significant difference although there appeared to be a trend towards more clinically focused articles and an increase in 'clinician authors'. In a survey of Australian nurse academics, Roberts (1997) found that 7% had published in refereed journals between 1993 and 1994. Of these, 26% were male although only 17% of nurse academics are men.

Jackson et al (1996) reviewed the content of four Australian refereed nursing journals: *Australian Journal of Advanced Nursing*, *Contemporary Nurse*, *Nursing Inquiry* and *Collegian* over the nine-month period, September 1994 to June 1995 and categorised this content according to subject matter and authorship by gender and discipline (Jackson et al 1996). Their findings indicated that articles pertaining to clinical practice, the practice of research, and professional nursing issues were well represented. They also noted a marked increase in the number of refereed Australian nursing journals since 1992 at which time there was only one. In reviewing the available literature on Australian authors it is of concern that Jackson et al (1996) found less than 50% of articles were generated by clinician authors, although they found over 30% were joint publications between academics and clinicians.

All three of the abovementioned investigations explored the content of articles while the aim of the present study was to generate a detailed account of research published by Australian authors. Refereed research articles were analysed from 11 nursing journals. The data included: number, gender, discipline base, place of employment and geographic location of authors as well as an indication of research interests.

METHOD

The present study involved a quantitative approach using content analysis in order to describe information found within refereed research article abstracts on the characteristics of the authors.

Selection of journals

In order to ensure information documented would accurately represent nursing research and development produced from Australia, 20 refereed nursing journals were selected from publishing bases in: Australia (A), United Kingdom (UK), the United States of America (USA), and Japan, for the years January 1995 to December, 2000. This list included: *Advances in Nursing Science* (USA), *Australian Journal of Advanced Nursing* (A), *Australian Journal of Critical Care Nursing* (A), *Australian Journal of Holistic Nursing* (A), *Australian Journal of Rural Health* (A), *Collegian* (A), *Contemporary Nurse* (A), *International Journal of Nursing Practice* (A), *International Journal of Nursing Studies* (USA), *Journal of Advanced Nursing* (UK), *Journal of Clinical Nursing* (UK), *Journal of Continuing Education in Nursing* (USA), *Journal of Nursing Education* (UK), *Journal of Nursing Administration* (USA), *Nurse Education Today* (UK), *Nursing Inquiry* (A), *Nursing and Health Science* (Japan), *Professional Nurse* (UK), *Research in Nursing and Health* (USA), *Western Journal of Nursing Research* (USA) and *Nurse Education Today* (UK). Journals found to contain less than 10 research articles from Australian authors in the time period January 1995 to December 2000 were not used. Thus articles from 11 journals were included in the final analysis.

Article retrieval

Two supervised student researchers based in Sydney and Adelaide, respectively, collected the data. Coordination and consistency of data collection and entry for the project was maintained through extensive email and telephone contact. Two methods of article retrieval were used in the study. In Adelaide, a manual search of journals was conducted and refereed articles were chosen by reading abstracts to verify their research basis and Australian authorship. All abstracts including authorship details were photocopied. In Sydney, the journals were accessed on line through the databases CINAHL and MEDLINE (1995-2000), for reference details and abstracts. The use of online databases for this type of content analysis was used for the earlier studies in the UK (Rafferty et al 2000) and in Australia (Jackson et al 1996). Lists of all articles published by each journal were printed out and the reference details were used to select articles that contained at least one Australian author. These articles were then printed and perusal of abstracts identified whether or not the articles pertained to research. More detailed author information (where two or more authors were cited) was retrieved using full text options within the electronic databases or by conducting a manual library search.

In order to verify the inter-reliability of the two methods used to select journals, a comparison of the research articles retrieved from the *AJAN* was conducted. There were 93 articles found by the electronic method and 92 from the hand sort, which represented an error of 1%.

Data collection

The Statistical Package for Social Science (SPSS) Version 10 was used to create a template for data collection according to the broad list of variables. These included journal source, year of publication and classification of research topic. Gender was assigned according to the author's first name when available. When cited, data were collected on discipline base, place of employment and geographic location of authors. Each variable contained a number of categories by which each article was coded.

Data analysis

Coded categories for each variable were tallied and descriptive analysis processed with frequencies, means, medians and standard deviations calculated. Results were tabulated for comparison, while cross tabs between selected variables were examined to determine relationships.

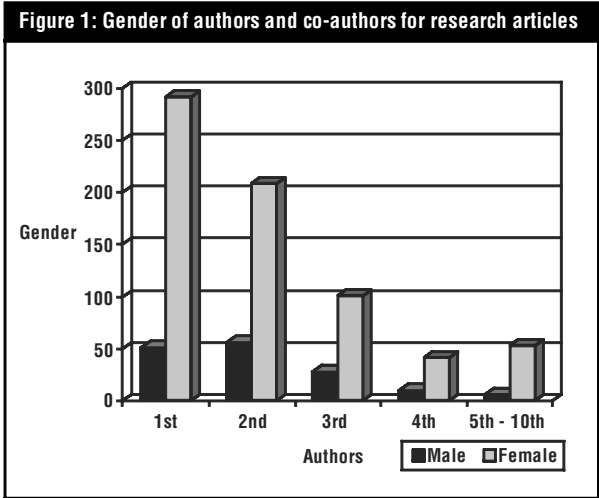
RESULTS

Journals used in the final analysis were limited to those that contained 10 or more articles with at least one Australian author since the journals accessed were from general nursing journals and not specialist journals. Selection of Australian authorship was determined if the author's contact details were based in Australia. Of the journals analysed, seven were Australian based and four were located in the UK. The final selection of journals was: *Australian Journal of Advanced Nursing* (A), *Australian Journal of Critical Care Nursing* (A), *Australian Journal of Holistic Nursing* (A), *Collegian* (A), *Contemporary Nurse* (A), *International Journal of Nursing Practice* (A), *International Journal of Nursing Studies* (USA), *Journal of Advanced Nursing* (UK), *Journal of Clinical Nursing* (UK), *Nurse Education Today* (UK) and *Nursing Inquiry* (A).

A total of 509 refereed research articles were analysed representing 12.5% of the possible 4062 articles published by the journals used in the final analysis as shown in table 1. Over 60% of the articles analysed were from Australian journals. The three major journal sources of the research articles were the *AJAN* (93 articles, 18.3%), *Journal of Advanced Nursing* (JAN) (92, 18.1%) and *International Journal of Nursing Practice* (IJNP) (73, 14.3%).

The 509 articles analysed were by a total of 1112 authors. The number of authors per paper ranged from one to 10 with one or two authors being the most common. The mean number of authors per paper was 2.18. Figure 1 depicts the number of authors where gender could be determined in order of authorship. As shown in the figure

Table 1: Number of research articles with Australian authors in journals accessed (A=Australian, UK=United Kingdom) Total number of refereed research articles n=509			
Journal name	Total articles 1995-2000	Research articles with Aust. author n %	
Australian Journal of Advanced Nursing (A)	164	93	57
International Journal of Nursing Practice (A)	205	73	36
Contemporary Nurse (A)	209	58	28
Aust Journal of Critical Care Nursing (UK)	182	40	22
Collegian (A)	216	45	21
Nursing Inquiry (A)	206	27	13
Nurse Education Today (UK)	175	21	12
International Journal of Nursing Studies (UK)	289	22	8
Australian Journal of Holistic Nursing (A)	250	19	8
Journal of Advanced Nursing (UK)	1802	92	5
Journal of Clinical Nursing (UK)	364	19	5
TOTAL	4062	509	12.5



of the total of 845 authors, 151 (17.8%) were male; and of these 51 of 342 (14.9%) were first authors. It is of interest that further analysis (data not shown) elucidated that of the first and second authors 26 researchers were cited more than three times with one researcher having 12 publications. Of these more prolific authors, six were men and seven held a joint appointment between a hospital and university. The total research papers by these 26 authors acting as first or co-authors was 120, ie 23.7% of the 509 research articles found in the study.

If available in citation, the discipline or field of study of the authors were tallied and tabulated as shown in table 2. The most common discipline of the first author was 'nursing' (403, 83.6%) with 'health science' (27, 5.7%) and 'student' (13, 2.7%) following in order. Medicine was the discipline of the first author in 11 (2.3%) of the cases. These percentages are calculated on the 482 first authors on which the information was available.

The top 10 research interests of the authors which were determined from citation details were education of nurses (95, 18.7% of major topics of articles analysed), practice

Table 2: Discipline and area of employment of authors and co-authors for research articles					
Author origin	1st author n (%)	2nd author n (%)	3rd author n (%)	4th author n (%)	5th-10th author n (%)
Discipline					
Nursing	403 (83.6)	202 (72.4)	103 (73.0)	40 (75.5)	50 (83.3)
Health Science	27 (5.7)	9 (3.2)			
Student	13 (2.7)	2 (0.7)	1 (0.7)		
Medicine	11 (2.3)	17 (6.1)	15 (10.6)	3 (5.7)	2 (3.3)
Education	6 (1.2)	12 (4.3)	4 (2.8)		
Midwifery	6 (1.2)	4 (1.4)	2 (1.4)	2 (3.7)	1 (1.6)
Psychology	5 (1.1)	8 (2.9)	2 (1.4)	1 (1.9)	
Social Work	3 (0.6)	1 (0.3)			
Management	3 (0.6)	4 (1.4)	1 (0.7)	1 (1.9)	2 (3.3)
Other	2 (0.4)	7 (2.5)	2 (1.4)	1 (1.9)	
Communi-cation	1 (0.2)				
Occupational Therapist	2 (0.7)	1 (0.7)			
Pharmacy	1 (1.9)	1 (1.6)			
Sociology	5 (1.8)	3 (2.1)	1 (1.9)		
Total	482 (100)	279 (100)	141 (100)	53 (100)	60 (100)
Area of employment					
University	343 (69.7)	181 (63.7)	78 (54.9)	25 (49.0)	17 (28.8)
Health	105 (21.3)	86 (30.2)	53 (37.3)	21 (41.1)	32 (54.2)
University and health	37 (7.5)	14 (4.9)	10 (7.0)	4 (7.8)	10 (16.9)
Other	7 (1.4)	3 (1.0)	1 (0.7)	1 (1.9)	
Total	492 (100)	284 (100)	142 (100)	51 (100)	59 (100)

issues (78, 15.3%), professional issues (46, 9.0%), aged care (28, 5.5%), occupational health (22, 4.3%), acute care (21, 4.1%), service delivery (18, 3.5%), research issues (18, 3.5%), mental health (17, 3.3%) and maternal and infant care (17, 3.3%).

When examining the paradigm in which the research was conducted of the 495 cases in which this was cited 203 (41.0%) were quantitative, 230 (46.5%) were qualitative and 62 (12.5%) were a mix of quantitative and qualitative methods (data not shown). When a cross tab of discipline or field of study of the first author of article and paradigm was conducted there was a similar ratio of quantitative to qualitative methodology if the discipline area was nursing. However, if psychology or medicine was the discipline area of the first author there appeared to be a preference for quantitative methods (80% and 64% of articles respectively).

The area of employment of the authors was tallied and tabulated if acknowledged in the publication (table 2). It can be seen that the most common place of employment was a university (644, 62.5% of total authors cited) followed by authors employed by health organisations (297, 29.0%). Authors with joint appointments between university and health organisations comprised 75 (7.3%) of the total.

The geographic locations of the Australian based authors for which the information was provided are displayed in figure 2. The number in each capital and the rest of the state are depicted. Most authors came from New South Wales (38.7%), followed by Queensland (18.7%), Victoria (18.6%) and South Australia (12.5%). This trend is similar to the first authorship with 36.2% from NSW,

although 21.9% came from Victoria, 17.9% from Queensland and 13.4% from South Australia. Twenty four authors (2.3%) were from the UK, USA, Canada or Asia. Of these, three were first authors.

Figure 2: Location of authors



DISCUSSION

While it needs to be remembered that this study did not examine specialist nursing or medical journals, it has confirmed the evidence from previous research in Australia that few nurses, even if they are academics, are publishing research papers in refereed general nursing journals (Daly 1990; Jackson et al 1996; Roberts 1997). Only 12.5% of the possible articles in the journals examined were based on research. The data tend to reflect that the publication output of nurses may be even lower than other disciplines.

It is suggested in the literature in the UK (Mulhall 1996) that much of the published material in nursing literature is produced only by a few. In an Australian study of academics, Ramsden (1994) found that publications rates were variable with most publications being the work of a minority of staff. This is confirmed in this study with 26 authors publishing 23.6% of the research articles.

The historical trend that most authors of published articles come from the university sector continues in this study (Daly 1990; McConnell and Paech 1994; Jackson et al 1996). It has been suggested that joint professorial appointments between hospitals and universities provide a means of addressing the lack of research publication in nursing (Dunn and Yates 2000). However, this study has shown that joint appointees account for only 7.3% of all articles analysed. Nevertheless they were identified as seven of the more prolific 26 researchers who were first or second author in 23.7% of articles. While these appointments are bringing the stakeholders, ie the academics and clinicians together, more work and

appointments are needed before full evaluation of these positions in enhancing research publication can be made.

In her article, Dunn (1991) indicated that most of the clinical professors in their study felt a crucial component of their role was to involve clinicians in research publication. As well Megel et al (1998) suggest that high producers of nursing research publications in the US spent more time on research and writing than on teaching and that publication increased after a doctorate was obtained. This needs to be investigated in the Australian context. Actual data on the submission of research articles to journals by Australian nurse researchers are not available so the issue of rejection rates by individual journals cannot be estimated although it may be a factor to consider in analysing actual researcher output.

In the UK study by Rafferty et al (2000) the *JAN* was rated as the journal with the most influence on practice and in this study it was seen to be favoured by Australian authors along with the *AJAN*. The propensity to publish in *AJAN* may reflect the trend reported by Nagy et al (1992) that the most highly rated journals RNs used to source for information were the *AJAN* along with the *Australian Journal of Critical Care*.

It is difficult to draw conclusions from the geographic location of authors. However, it is of interest that authorship is not in any way limited to capital cities and reflects the spread of university campuses in rural and metropolitan areas (figure 2). Given the relative size of its population, South Australia appeared to do well in terms of authorship. This may however be a reflection of the location of three universities in Adelaide, each of which has a school or department of nursing.

Similar to Rafferty et al's (2000) study in the UK, this study has revealed that the majority of the articles were authored by one or two people (figure 1). A lack of interdisciplinary collaboration has been the norm in nursing which has drawn criticism as an introspective discipline (Marquis et al 1993). However, as displayed in table 2, there is an indication that collaboration across other disciplines is developing, particularly with colleagues in health science, medicine and psychology.

CONCLUSION

This study has shown that publication of refereed research articles by Australian nurses is low in relation to the total articles in the journals analysed. As a profession and discipline, nurses need to publish their research in order to improve standards of nursing practice. If nurses do not share their knowledge the body of nursing knowledge is not enhanced while others may expend time and resources repeating research unnecessarily. In this era of evidence based practice, knowledge that is generated from research is regarded as imperative. While other forms of nurse publications are vital, this study recognises the value of research as a major contribution in developing

and improving nursing standards of practice. For practitioners to utilise and implement such knowledge it must be widely disseminated and in journals that are easily accessible and readable.

This study was limited in that it only examined general nursing journals and most of the journals finally analysed were Australian based. It would be useful to survey the authors to determine why they choose particular journals for their publication and how often they are rejected by individual journals.

REFERENCES

- Blunt, J., Savulescu, J. and Watson, A.J.M. 1998. Meeting the challenges facing research ethics committees: Some practical suggestions. *British Medical Journal*, 316:58-61.
- Chalmers, I. 1993. The Cochrane Collaboration: Preparing, maintaining and disseminating systematic reviews of the effects of health care. *Annals New York Academy of Science*, 703:156-165.
- Daly, S. 1990. The metamorphosis of nursing research in Australia. Proceedings of Nursing Research in Action - Dreams, Deliberations and Discoveries. Adelaide: The Royal Adelaide Hospital. 121-128.
- Dunn, B. 1991. Who should be doing the research in nursing? *Professional Nurse*, 6(4):190-196.
- Dunn, S. and Yates, P. 2000. The roles of Australian chairs in clinical nursing. *Journal of Advanced Nursing*, 31(1):165-171.
- Goody, J. 1977. *Domestication of the savage mind*. Cambridge England: Cambridge University Press.
- Hicks, C. 1992. Of sex and status: A study of the effects of gender and occupation on nurses' evaluation of nursing research. *Journal of Advanced Nursing*, 17:1343-1349.
- Hicks, C. 1995. The shortfall in published research: A study of nurses' research and publication activities. *Journal of Advanced Nursing*, 21(3):594-604.
- Jackson, D., Raftos, M. and Mannix, J. 1996. Through the looking glass: Reflections on the authorship and content of current Australian nursing journals. *Nursing Inquiry*, (3):112-117.
- Marquis, B., Lillibridge, J. and Madison, J. 1993. Problems and progress as Australia adopts the Bachelor's degree as the only entry to nursing practice. *Nursing Outlook*, 41(3):135-40.
- McConnell, E., and Paech, M. 1994. Trends in scholarly nursing literature. *The Australian Journal of Advanced Nursing*, 11(2):28-32.
- Megel, M., Langston, N.F. et al. 1988. Scholarly productivity: A survey of nursing faculty researchers. *Journal of Professional Nursing*, 4(1):45-54.
- Mulhall, A. 1996. Publishing original research: Principles and practice. *Nursing Research*, 4(1):49-61.
- Nagy, S., Crisp, P. and Brody, L. 1992. Journal reading practices of RNs in NSW public hospitals. *The Australian Journal of Advanced Nursing*, 9(2):29-33.
- Rafferty, A.M., Traynor, M. and Lewison, G.M. 2000. *Measuring the outputs of nursing research and development*. London: Centre for Policy in Nursing Research.
- Ramsden, P. 1994. Describing and explaining research productivity. *Higher Education*, 28(2):207-226.
- Rix, G. and Cutting, K. 1996. Research interests: A study of proposals submitted for approval. *Nurse Researcher*, 3(3):71-79.
- Roberts, K. 1997. Nurse academics scholarly work. *The Australian Journal of Advanced Nursing*, 14(3):5-14.
- Royal College of Nursing, Australia. 1998. *The directory of nursing research in Australia* (5th ed) RCNA: Melbourne.
- Smith, J. 1996. The role of nursing journals in the advancement of professional nursing. *Journal of Advanced Nursing*, 23(1):12-16.
- Styles, M.M. 1978. Why publish? *Image: Journal of Nursing Scholarship*, 10:28-32.
- Traynor, M. and Rafferty, A.M. 2000. Research Revealed. *Nursing Standard*, 14, (45):35-37.
- Wallace, M.C., Shorten, A. and Russell, K.G. 1997. Paving the way: Stepping stones to evidence based nursing. *International Journal of Nursing Practice*, 3(3):147-152.
- Walsh, M. and Ford, P. 1992. *Nursing rituals: Research and rational actions*. Oxford: Butterworth-Heinemann.
- Winslow, E.H. 1996. Failure to publish research a form of scientific misconduct. *Heart & Lung: The Journal of Acute and Critical Care*, 25(3):169-171.
- Ziman, J.M. 1968. *Public knowledge*. Cambridge, England: Cambridge University Press.

LIMIT SETTING: A USEFUL STRATEGY IN REHABILITATION

Julie Sharrock, RN, CritCare Cert, PsychNursCert, BEd, MHSc (Psych.Nurs.), is Psychiatric Consultation-Liaison Nurse, St Vincent's Mental Health Service, Melbourne, Australia

Nonie Rickard, RN, RehabCert, GradDipBus, is Assistant Director of Nursing - Staff Development, Royal Talbot Rehabilitation Centre, Melbourne, Australia

Accepted for publication February 2002

Key words: limit setting, therapeutic milieu, challenging behaviour, rehabilitation

ABSTRACT

Limit setting is a concept familiar to most mental health clinicians, but much less familiar to staff not specifically trained in mental health care. This paper presents guidelines developed for rehabilitation staff on the strategy of limit setting. The aim of these guidelines was to provide a starting point for ongoing education on limit setting and behavioural management for staff working in a non-psychiatric rehabilitation environment. Limit setting is presented, not only as a response to challenging behaviour, but also as fundamental to all patient care within the rehabilitation context. The guidelines draw on the concepts of limit setting, acting out, therapeutic relationships and therapeutic milieu as described in the psychiatric literature. A humanistic framework for helping people underpins the guidelines. Principles for selecting and enforcing limits are described. Finally, a list of clarification prompts is provided for clinicians to use when faced with challenging patient behaviour.

INTRODUCTION

The purpose of this paper is to present guidelines developed for staff on the concept of limit setting in a rehabilitation environment. The guidelines evolved from a working party established to explore and improve the care of patients presenting with challenging behaviour. Limit setting is a concept familiar to most mental health clinicians but much less familiar to staff not specifically trained in mental health care. The aim of these guidelines was to provide a starting point for ongoing education on limit setting and behavioural management for staff working in a non-psychiatric rehabilitation environment. They were also used to support psychiatric consultations made to the rehabilitation centre in relation to the care of particular patients with challenging behaviour who had been referred to the psychiatric team. It is important to note that limit setting was identified by the working party as one of a number of strategies utilised when addressing challenging behaviour in a hospital environment. This paper does not seek to address the full range of strategies but is confined to limit setting.

BACKGROUND

The Royal Talbot Rehabilitation Centre (RTRC), a campus of the Austin and Repatriation Medical Centre in Melbourne, Australia, is a 100-bed inpatient rehabilitation facility. It provides inpatient and community services to people following brain injury, neurological, orthopaedic and spinal cord injuries.

The very nature of the medical diagnoses of patients undergoing rehabilitation, eg brain injury and neurological conditions, means that staff are expected to effectively manage patients with challenging behaviour. However, anecdotal evidence suggested that factors other than medical diagnoses influenced the likelihood of patients presenting with challenging behaviour and possibly being involved in a critical incident. Approximately every three to four months, a patient-related critical incident that affected staff work performance and/or safety occurred at RTRC. Patients with personality, substance abuse and psychiatric disorders were more likely to be involved in

critical incidents. The Challenging Behaviour Working Party was established in response to a series of critical incidents that staff found difficult to manage, particularly because of the co-morbid mental health issues and nature of the behaviour exhibited.

The Working Party, of which the authors were members, was multidisciplinary in nature and included personnel from a range of clinical backgrounds. Examples of challenging behaviour considered by the Working Party included verbal and physical aggression, manipulation, anti-social, loud and offensive language, self-harm, substance abuse, harassment and any activity that interfered with the safety and well being of others.

The aim of the working party was to develop a range of strategies to improve the management of patients with challenging behaviour and prevent critical incidents. In addition to the limit setting guidelines presented here, other initiatives included:

- Development of a patient drug and alcohol policy utilising a harm minimisation approach.
- Drug and alcohol education for staff.
- Exploration of a debriefing model ensuring 24-hour access for staff and patients following critical incidents.
- Further development of the relationship between RTRC and the Consultation-Liaison Psychiatry Service.
- Mental health and psychiatry education for staff.

LITERATURE REVIEW

To inform the working party in addressing the issue of challenging behaviour in the rehabilitation environment, the literature was consulted. There were no systemic reviews or clinical practice guidelines found in relation to limit setting. The majority of journal articles and texts available that addressed this concept were within psychiatric (eg Neale and Rosenheck 2000; Milton and Watt McMahon 1999; Schultz and Dark Videbeck 1998; Chatoor et al 1997; Rosenheck 1995; Stuart and Sundeen 1995; Lancee et al 1995; Love and Seaton 1991; DeLaune 1991) and psychotherapeutic (eg Gorney 1994; Pam 1994; Hawton et al 1989; Lerner 1987) literature. This literature was presented in language for an audience familiar with the concepts of psychiatry, not for staff not specifically trained in this area. For the purpose of this discussion, the theory of limit setting as understood in psychiatry will be briefly described.

The origins of limit setting are from psychoanalytical theory. According to Gorney '...limit is understood to be a boundary between self and others, established as an interactional dimension of experience' (1994, p.77). Drawing on Erikson's theory of development, Gorney (1994) explained that the core task of childhood and adolescence is the establishment and integration of personal limits and increasing an awareness of and respect for the limits of others. In other words, developing the ability to set one's own limits is part of the maturing process.

When a person is unable to set personal limits, one response is to engage in *acting out* behaviour. Acting out behaviour can be a conscious or unconscious endeavour for limits to be set and may be aimed at testing out the authority of another. It can also be an attempt to communicate something that cannot be communicated in another way. Acting out behaviour can be destructive, disruptive, anti-social and problematic for those attempting to help that person (Pam 1994). If it is not addressed, such behaviour is often counterproductive to the patient's integration into a fulfilling life. If it is not contained in the rehabilitation environment it affects the person's rehabilitation and can also affect other patients.

In response to acting out, the therapist sets limits on behaviour and sets out the boundaries within which the person is expected to behave. The therapist acts as a '...firm but fair authority figure who sets standards and inculcates responsibility' (Pam 1994, p.433). The therapist also reaches '...out to the healthy ego of the patient, to whatever capacity he or she possesses to understand the underlying issue and to move toward autonomy' (Pam 1994, p.435). The client usually initially resists and resents the limits and may respond with anger because of the authoritative nature of the intervention. However, the goal is that with time and assistance from the therapist in addressing the underlying issues, more adaptive reactions, healthier expression of emotions and containment of disruptive behaviour is achieved (Pam 1994).

While limit setting as a concept arose from psychoanalytical theory, the development of different models of psychotherapy over the past decade has led to a degree of overlap in notions and techniques. For example, the term limit setting is not used in *behavioural therapy* but given that this type of therapy has a focus on learning (Bloch and Harari 2001), there are parallels. Behavioural therapy has expanded since the days of Pavlov's dogs and Skinner's pigeons and now forms a group of approaches that have a focus on assisting people to change behaviour through encouraging desirable behaviour and discouraging (and ultimately extinguishing) undesirable or negative behaviour. *Social learning theory* recognises the interdependence of cognition (thoughts and beliefs), environment and behaviour and incorporates this idea in understanding how learning within a social context occurs. Role modelling is a powerful phenomenon that is recognised within this theory (Bloch and Harari 2001), a process also utilised in limit setting. *Cognitive behaviour therapy* combines the work of the behaviourists with the cognitive model of understanding behaviour and emotion pioneered by Aaron Beck and Albert Ellis (Bloch and Singh 2001). This model of psychotherapy utilises a range of techniques aimed at reducing psychological distress and modifying emotional and behavioural responses (Hawton et al 1989). Understanding the cognition and emotion behind the behaviour is important in limit setting.

Pam (1994) identified a sparsity of literature on limit setting and suggests that mental health workers learn about the concept and develop the skill through peers in the

clinical setting. He further added that the theoretical framework for the concept of limit setting is not well documented in the literature and this omission needs redress. Given this, it is not surprising that few papers were found that discussed limit setting in the non-psychiatric context.

Grossman (1997) presented a case study of a 39-year-old man with quadriplegia, an intravenous drug user who was HIV positive. This patient's problems presented many challenges in the delivery of nursing care including endless complaints to staff, bursts of anger, abuse and blaming, avoidance of the patient by staff and multiple conflicts with and between staff. Limit setting was one of a number of strategies employed in the successful care of this patient. This strategy was set within a multidisciplinary care plan that was consistent and holistic. Staff support was provided in the form of education, team building, stress management and team meetings. The outcome was that the difficult behaviour was contained and the patient's care progressed to a positive end where he died as a 'loved member of the unit' (Grossman 1997 p107).

Gans (1983) presented four case scenarios within the rehabilitation environment. The common theme in each of these was hate: patient self-hatred, patient-staff hatred and staff hatred of patients and their families. He described problematic behaviour emanating from these clinical situations and again limit setting was suggested as a useful strategy. However, specific detail on the implementation of this strategy was not provided.

Smith (1978) discussed limit setting in a general hospital environment and she provided some practical guidance in the use of this strategy. She highlighted the importance of self-awareness, attitude, confidence, firmness, clarity, consistency, planning, staff communication and staff support in effective limit setting.

There were numerous articles relating to the care of specific problem behaviour and discussion of the concept of the *difficult* or *troublesome* patient (example Morrison et al 2000; Gatward 1999; Wolf et al 1997; Daum 1994; Procter 1992; Pelletier and Kane 1989; Antai-Otong 1989). Limit setting was referred to in many of these articles as a strategy when managing such behaviour. While this body of literature was useful in that it stimulated discussion and understanding of the issues related to challenging behaviour, it did not provide the detail on limit setting as a strategy that the working party was seeking.

THE GUIDELINES

In light of the lack of literature that provided clear and specific guidance in the implementation of limit setting as a strategy framed in language that was understandable to non-psychiatric clinicians, the following guidelines were developed. These guidelines provided the starting

point for further education on limit setting and behavioural management for staff. It is not proposed that the guidelines are applied rigidly but summarise a set of principles and viewpoints that can contribute to patient care planning.

Within the guidelines, limit setting is presented, not only as a response to challenging behaviour, but also as fundamental to all patient care within the rehabilitation context. The guidelines draw on the concept of limit setting as described previously. In addition, notions of the therapeutic relationship and therapeutic milieu have influenced these guidelines. A therapeutic relationship is between a professional and client that is time limited, goal orientated and focussed on positive health outcomes for the client (Queensland Nursing Council 1997). A therapeutic milieu is an environment that is structured and maintained with the aim of maximising the opportunity for patients to achieve health orientated goals, both physically and psychologically (Schultz et al 1998).

A humanistic framework for helping people underpins the guidelines. This view or set of values is based on the work of Maslow (1968), Rogers (1961), Bugental (1963), Yalom (1981) and May (Corsini and Wedding 1981) and has contributed to the body of knowledge utilised within the social sciences in understanding and interacting with human beings and assisting individuals to change and grow. The humanistic view of human beings is hopeful and includes a belief that there is an inherent drive within each individual toward a strong sense of self, self-awareness, self-determination, responsibility, trustworthiness and creativeness. Given an environment of trust, positive regard, genuine communication and understanding (empathy) then individuals can move toward healthier and more productive lifestyles (Rogers 1961). The importance of the trusting, confiding or therapeutic relationship now underpins psychotherapy (Bloch and Harari 2001).

The principles for selecting and enforcing limits are described. A list of clarification prompts is provided for clinicians to use when faced with challenging patient behaviour.

GUIDELINES FOR LIMIT SETTING

The establishment and maintenance of limits are essential to the operation of a hospital and the wards and units within it. Limits provide a framework from within which patients, staff and visitors can function. Although limit setting is often raised in response to situations where a person's behaviour is creating some disturbance, it should be remembered that limits are part of everyday life. We all feel more secure when we receive clear and unambiguous messages, when we know what the rules are and what is expected of us and that these expectations are consistent. We are able to function more productively when the goal posts do not keep shifting.

Limit setting is also used to describe a therapeutic strategy utilised in the care of patients that have difficulty setting limits on their own behaviour, eg patients with cognitive impairment or personality disorder. In the context of a hospital it is the communication of boundaries and expectations within the relationship between patient and staff. The establishment of boundaries provides a structure, a sense of caring, and can provide a sense of relief and a greater sense of control for the patient. They are essential to the maintenance of a therapeutic professional relationship or alliance between the patient and the staff and minimise manipulation by and secondary gains for the patient. Limit setting does not ensure behavioural change but it does set parameters for acceptable behaviour and gives the patient the best chance to change reactions and behaviour if s/he has the skills and is willing to do so.

Principles to remember when selecting limits

- Limits must be consistent with policy and reflect the philosophy of the hospital and the unit.
- Staff must be aware that they are role models for the limits they set. Their behaviour must be consistent with what is expected of the patient and visitors.
- Patient information and orientation processes must reflect these limits consistently and clearly and yet be flexible enough so that individualised care planning can be provided.
- Limits should be clear and simple with a clear rationale, ie have some therapeutic and/or practical aim. Do not set unnecessary or controlling rules without clear reasoning.
- Teamwork and consistency are essential. Where possible, the limits selected are understood and supported by the majority of staff involved in the care of the patient.
- Limits must be selected so that the staff have the best chance to maintain the limits consistently on all shifts, remembering that staff are not robots and unexpected contingencies will always arise.
- Some actions have natural consequences and these can provide a basis for the selection of limits and add strength to their rationale, eg - if a patient stays in bed in one position all the time then s/he will develop pressure sores and is at risk of developing other complications.
- Individualised consequences of breaking limits can be selected but these need to be considered very carefully, be realistic and enforceable.
- Some limits can be renegotiated, others cannot especially those that are beyond the control of the staff.
- Limits are documented in the management plan.
- Limits can be documented in a formal written agreement that is signed by both patient and staff. An agreement should not be an isolated intervention but embedded within the broader principles. It is

important to remember that this is not a legally binding contract but reinforces the commitment on behalf of the patient and the staff toward health outcomes for the patient.

Principles to remember when enforcing limits

- Limits are *clearly* and *simply* stated in a non-punitive/non-condemning manner. Explain clearly what behaviour is inappropriate and what is expected of the person.
- They should include a brief *rationale* without entering into extensive debate, agreement or rationalisation.
- *Negotiate* only those limits that are negotiable.
- Explain the *natural* consequences of actions. Example: 'if you...then...will happen'.
- If *consequences* are used they should be enforced as soon as possible after breaking the limit.
- Do not make *threats* or set consequences that cannot be followed through.
- Offer *alternative* actions/options/behaviour. Example: 'I don't like it when you....I would prefer if you.....'
- Be *mindful of the feelings* of loss of control people often experience in hospital.
- If you *anticipate* that there is likely to be testing of limits by a patient, *plan* your responses in advance.
- Be *clear* in your own mind what the limit is and why it is necessary.
- Do not give mixed messages by making exceptions by wanting to be the 'only', 'special' or 'favourite' one. Be *aware* of your own motivations and reactions to the person's behaviour and situation. Provide support to each other by giving the team an opportunity to discuss interactions with patients and visitors. This helps the team maintain clarity and cohesiveness, particularly in difficult situations.

Limit setting within the broader context

Effective limit setting can only occur within the context of a supportive and collaborative relationship with the patient, in a caring environment that respects the rights of the individual.

- Every patient is viewed as a whole person who must be cared for with consideration given to his/her social/cultural/spiritual context.
- Physical, psychological and social health are interrelated.
- Each patient is accepted as an individual and treated with respect, honesty and a genuine sense of caring for that patient as a person. Accepting the person does not mean that all behaviour is accepted.
- Each patient has ultimate responsibility for their health (except in patients with clearly diminished capacity). Generally patients opt toward healthier and more productive lifestyles whenever they are able. All behaviour has motivating factors that may not always be obvious to or easily understood by the observer.

Some behaviour is directed at satisfying an immediate need yet is damaging in the long term. You can only facilitate awareness of the need for change but cannot force it.

- Care is provided for patients when they are dependent and the goal is to work toward the greatest level of independence possible. Staff do for patients what patients cannot do for themselves. Staff work toward independence by working *with* the patients, not doing things *to* them.
- Health care is collaboration between the patient and the staff working toward negotiated health orientated goals. This can be viewed as a therapeutic professional alliance/relationship. A therapeutic relationship is a relationship between a professional and client (either patient or family/significant other) that is time limited, goal orientated and focused on positive health outcomes for the client. Trust is fundamental to this relationship.
- The ward environment is structured and maintained with the aim of maximising the opportunity for patients and staff to work together to achieve health orientated (both physical and psychological) goals for the patient. Clear communication processes, both verbal and written, are in place. Physical and psychological safety is maintained.
- It is acknowledged that hospitalisation is a stressful event and that living within the artificial environment that operates within a structured framework can be challenging for many patients.
- Confidentiality is maintained but confidentiality is always qualified as each staff member works within a team.
- Supporting patients' self esteem and self-image during a time when it may be under threat is essential. This is done through having realistic expectations, giving positive feedback and being supportive of attempts at healthy behaviour, no matter how small. It is considered important to respond to the behaviour and not the person.
- A multidisciplinary team approach to patient care utilises a mix of skills to assist the patient.

When faced with behaviour that is a problem the following areas should be considered:

1. Define the behaviour.
2. Identify the problem/risk associated with the behaviour (to patients, others, staff).
3. Identify the relationship between the behaviour and the clinical condition(s).
4. Identify related policy and legislation.
5. Identify the philosophical and ethical questions raised.
6. Identify what the preferred/required behaviour is.
7. Identify precipitants to and reinforcers of the behaviour.

8. Consider what else (eg emotions, conflicts) might be contributing to the behaviour.
9. Establish if there is patient-motivation to change the behaviour.
10. Identify the strategies that can be utilised.
11. Identify potential difficulties in utilising strategies.
12. Identify who should be clear about the limits.

CONCLUSION

This paper presents limit setting as a useful strategy in the management of challenging behaviour within a rehabilitation environment. The intention is that the guidelines provide a practical framework within which clinicians can effectively care for all patients and in particular, those presenting with challenging behaviour. Preliminary utilisation of these guidelines has occurred in clinical and educational forums. This work has demonstrated that developing skills in effective limit setting is of benefit to staff working in a rehabilitation environment. However, it has also highlighted that these are complex interpersonal skills that require time to learn, commitment from the team, support from management and input from mental health experts so that staff can develop and utilise these skills appropriately and effectively. Finally, the lack of literature describing limit setting, particularly in the non-psychiatric environment, is of concern. It is intended that this paper will stimulate discussion and debate about the utilisation of this strategy in a range of environments as well as contribute to the body of knowledge in this area.

REFERENCES

- Antai-Otong, D. 1989. Dealing with demanding patients. *Nursing*. Jan:94-94.
- Bloch, S. and Harari, E. The psychotherapies. In Bloch, S. and Singh, B.S. (Eds) 2001. *Foundations of Clinical Psychiatry*. Carlton South. Victoria: Melbourne University Press.
- Bugental, J.F.T. 1963. Humanistic psychology: A new breakthrough. *American Psychology*. 18:563-567.
- Chatoor, I., Hirsch, R. and Persinger, M. 1997. Facilitating internal regulation of eating: A treatment model for infantile anorexia. *Infants and young children*. 9(4):12-22.
- Corsini, R.J. and Wedding, D. (Eds). 1989. *Current psychotherapies*. 4th edn. Itasca. Illinois: F.E. Peacock Publishers.
- Daum, A.L. 1994. The disruptive anti-social patient: Management strategies. *Nursing Management*. 25(8):46-51.
- DeLaune, S.C. 1991. Effective limit setting: How to avoid being manipulated. *Nursing Clinics of North America*. 26(3):757-764.
- Gans, J.S. 1983. Hate in the rehabilitation setting. *Archives Physical Medicine and Rehabilitation*. 64(4):176-179.
- Gatward, N. 1999. Managing the 'manipulative patient': A different perspective. *Nursing Standard*. 13(22):36-38.
- Gorney, J.E. 1994. On limit and limit setting. *Psychoanalytical Review*. 81(2):259-278.
- Grossman, S. 1997. How can nurses use limit setting to facilitate spinal cord patients' independence? *SCI Nursing*. 14(3):105-107.
- Hawton, K., Salkovskis, P.M., Kirk, J and Clark, D.M. 1989. *Cognitive behaviour therapy for psychiatric problems*. Oxford: Oxford Medical Publications.

- Lancee, W.J., Gallop, R., McCay, E. and Toner, B. 1995. The relationship between nurses' limit setting styles and anger in psychiatric inpatients. *Psychiatric Services*. 46(6):609-613.
- Lerner, J.A. 1987. Limit setting and the analyst's working. *American Journal of Psychoanalysis*. 47(3):243-249.
- Love, C.C. and Seaton, H. 1991. Eating disorders. Highlights of nursing assessment and therapeutics. *Nursing Clinics of North America*. 26(3):677-697.
- Maslow, A.H. 1968. *Toward a psychology of being*. 2nd edn. Princeton: Van Nostrand.
- Morrison, E.F., Ramsey, A. and Snyder, B.A. 2000. Managing the care of complex, difficult patients in the medical-surgical setting. *MEDSURG Nursing*. 9(1):21-26.
- Milton, I. and Watt McMahon, K. (eds) 1999. *Guidelines for the effective treatment of people with severe personality disorder*. Psychoz: Melbourne.
- Neale, M.S. and Rosenheck, R.A. 2000. Therapeutic limit setting in an assertive community treatment program. *Psychiatric services*. 51(4):499-505.
- Pam, A. 1994. Limit setting: theory, techniques, and risks. *American Journal of Psychotherapy*. 48(3):432-440.
- Pelletier, L.R. and Kane, J.J. 1989. Strategies for handling manipulative patients. *Nursing*. May. 19(5):82-83.
- Procter, N. 1992. Managing a 'difficult' client: An insight orientated approach. *Contemporary Nurse*. 1(1):43.
- Queensland Nursing Council. 1997. Appropriate nurse/patient relationships. *Queensland Nursing Forum*. 5(2) December: 22-28.
- Rogers, C. 1961. *On becoming a person: A therapists' view of psychotherapy*. London: Constable.
- Rosenheck, R. 1995. Substance abuse and the chronically mentally ill: Therapeutic alliance and therapeutic limit setting. *Community Mental Health Journal*. 31(3):283-285.
- Schultz, J.M. and Dark Videbeck, S. 1998. *Lippincott's manual of psychiatric nursing care plans*. 5th edn. Philadelphia: Lippincott.
- Smith, L. 1978. Limit-setting. *Nursing Times*. June 29:1074-1075.
- Stuart, G.S. and Sundeen, S.J. 1995. *Principles and practice of psychiatric nursing*. 5th edn. St Louis, Missouri: Mosby-Year Book.
- Wolf, Z.R., Brennan, R., Ferchau, L., Magee, M., Miller-Samuel, S., Nicolay, L., Paschal, D., Ring, J. and Sweeney, A. 1997. Research utilization: Creating and implementing guidelines on caring for difficult patients: a research utilization project. *MEDSURG Nursing*. 6(3):137-145.
- Yalom, I. 1981. *Existential psychotherapy*. New York: Basic Books.
-

HOME PARENTERAL NUTRITION: AN ETHICAL DECISION MAKING DILEMMA

Sarah Breier-Mackie, RN, MN, is a Clinical Nurse Specialist, Royal Hobart Hospital, Tasmania, PhD Candidate and Clinical Tutor, Faculty of Health Sciences, University of Tasmania, Australia

Christopher J. Newell, PhD, is a Consultant Ethicist and Senior Lecturer, Faculty of Health Sciences, University of Tasmania, Australia

Accepted for publication February 2002

Key words: ethics, narrative, quality of life, home parenteral nutrition

ABSTRACT

Ethics is a hot topic these days. Home health care providers need not be ethicists, however they do need to be able to identify problems quickly, and know how to address them. This paper explores the ethical issues arising from a narrative analysis involving an advanced cancer patient receiving Total Parenteral Nutrition (TPN) at home. It shows how complicated it is today to make nutrition support decisions that would have been customary less than 30 years ago. For and against arguments of TPN for advanced cancer patients are reviewed. Ethical positions adopted by the medical and nursing professions are explored and contrasted. The importance of patient autonomy, within a holistic notion of care, including decisions incorporating quality of life, are affirmed, providing a challenge to monitoring the status quo in approaches to decision making.

INTRODUCTION

The use of TPN for advanced stage cancer patients has significant ethical dimensions, showing the inter-relationship between ethical and clinical decision making. At times, all nurses can ask - are we prolonging life or prolonging death, and for whom are we providing the treatment? Ethical and legal issues concerning TPN for those with terminal illness are becoming increasingly significant to health care providers working in both the acute and home health settings. Certainly, the incidence of cancer patients receiving long-term TPN via complex vascular access devices in the home is increasing. The wisdom of this exercise is questionable when poor quality of life is often the outcome (Goodhall 1997), and this has resulted in a dichotomy of convictions. The ethical dimensions of withholding or withdrawing life-sustaining TPN, however, mirror the controversies reported in the literature. Part of the controversy is of course because of the fact that these people have a survival expectancy that varies markedly, typically from one to several months (Bozetti 1989).

There are numerous accounts in the literature discouraging the use of TPN for advanced cancer patients because of its expense, associated complications, and the complex ethical realities which confront us (Tchekmedyian 1993; Shaw 1992). This discussion in particular draws upon the experience of a 74-year-old woman (we will call her Margaret) who received TPN to manage intestinal malabsorption secondary to urological malignancy and radiation enteritis. The use of TPN prolonged her life considerably, but also led to complications, both from the TPN and those associated with the natural progression of disease.

Although TPN is increasingly considered as a possible treatment for patients with malignant disease but who are not suitable for surgery, reports on the issues in the literature regarding this practice are conflicting (Philip and Depczynski 1997). In brief, there are polarized extremes for and against such therapeutic intervention. Perhaps for

nurses this reflects the struggles over withholding and withdrawing the very therapy in which we are trained and socialised to spend so much of our energy, time and expertise. There is no question that we will need to be naming and facing these ethical dilemmas for a long time to come.

Setting the scene

This account relies upon the clinical experience of a nutrition nurse specialist and several other home health care nurses during 1998 in Tasmania. It utilises several narrative interactions between the patient and her home health nurses. Margaret's home TPN dilemma was recorded as verbatim journal entries made by the nursing team. Critical reflection upon such text provided the impetus for this account.

Before she was discharged home, Margaret endured almost four months of complex surgery and treatment for carcinoma of the bladder eventuating in severe radiation enteritis, formation of a high output enterocutaneous fistula, and numerous surgical revisions of her ileostomy and urostomy as a result of her underlying disease process. TPN was administered during this time via an implanted port. However, the level of consultation regarding long term effects of this therapy remained unclear. After this time in hospital, Margaret stated emphatically 'I want to go home', and regain some sense of 'normality' in life. For example, her bed and linen, bathroom, garden and cat figured prominently in defining such normality.

TPN was provided by her home health nurses who also attended to her many ostomy and wound care needs. When she did return home, Margaret was so relieved to be home that her mood improved, as did her clinical status. However it was not long until the clinical side effects of long term TPN set in, and Margaret began to suffer intractable nausea, vomiting and severe discomfort associated with her unmanageable electrolyte imbalances.

The home health care nurses felt helpless as their patient was totally overwhelmed by the many aspects of the home parenteral nutrition therapy - the pump, the supplies and equipment, and the distressing complications. Margaret became irritable and angry at her house and her private space being taken over by the medical supplies. Everywhere she turned there was something related to her surgery, her dressings, her bag changes and her line changes. Nausea became the biggest clinical problem and Margaret was now mentioning repeatedly 'I want it all to stop'. This situation resulted in the home health care nurses feeling extremely uncomfortable and helpless, despite all their efforts in delaying the complications of therapy. Margaret's notion of the risks and benefits of the treatment were at marked variance with that of her treating physicians, who saw the side effects of treatment as those they expected.

Margaret had many other complications related to her overall treatment, and the pressure on her family was becoming evident. Her elderly brother was not coping well with the situation, or the foreign technology in their home. Margaret would often say to the nurses who were tending to her TPN at home, 'Who is this for?', as she became more and more resentful of the side effects of treatment.

Hence, it had come to that time where an elderly woman with advanced cancer and related complications of treatment had simply, in her own words 'had enough'. In her words and actions she began fiercely to resent the treatment that was considered medically necessary. Despite her wishes, Margaret returned to hospital, where she died. She died in a place where she did not want to be, from numerous complications including those related to central venous access and sepsis.

This entire situation epitomised the silencing of the patient's true wishes, so often found in clinical settings. Also, it shows the way in which nursing concerns are often silenced or tacit in clinical decision making, where ethics appears to be defined in medical terms. It also showed how 'treatment' and the more holistic notion of 'care' can be different. Certainly the holistic notion of care is affirmed by the nursing literature (Curtin 1994; Goodhall 1997; Fawcett 1993).

The burden in reality

Margaret's treating physicians considered that her overall nutritional status and strength would improve with home TPN. Further, it was understood that there may be the potential for improvement in her depression/anxiety associated with long-term hospitalisation, and an improvement in her sense of well being upon returning home. On the other side of the loss/gain equation, the shortcomings of home TPN required analysis. TPN is a high-priced treatment in either the acute care setting of the hospital or one's home environment. Home TPN for Margaret placed further non-economic burdens on her elderly brother, as he needed to take responsibility for learning about and providing the TPN care, as a result of her overall weakness. Margaret also had to withstand the disappointment of her worsening clinical status when it did not improve with home TPN. Home TPN also represented an inherent risk for complications related to central venous access, infection and metabolism. However, it appears that home TPN did prolong Margaret's life with minimal nutritional benefits. Yet, it actually magnified her discomfort, anxiety and suffering - consequently diminishing her quality of life.

Arguments promoting TPN in cancer therapy

This case raises the need to differentiate between aggressively treating malnutrition in a cancer patient, and providing TPN to an advanced cancer patient who is dying. This discussion is not refuting treatment of malnutrition in the many cancer patients who need more kilojoules than they can consume. It has been documented

that patients with cancer who maintain their body weight have a better prognosis (Daly et al 1990; De Wys et al 1980; Bozetti 1989). Cancer provides significant stress to the body, frequently causing cachexia as the body 'cannibalises' its own protein reserves in a process of catabolism. Quillin (1998) describes tumors as major parasites that drain nutrient reserves from the person while blunting the appetite. Grant (1990) estimated that 40% or more of cancer patients actually die from malnutrition, and not from cancer. He contends that nutrition therapy including parenteral feeding is the only treatment for malnutrition in specific cases.

Mayo (1996) argues that nutrition is 'basic' care that cannot be withheld or withdrawn. This argument takes a number of varying forms, all of which emphasise the basic nature of the treatment discussed. Some authors have perceived nutrition as a necessity of life or as routine comfort care regardless of how it is provided (Mayo 1996; Watts and Cassell 1984). A related contention is that nutrition is usually provided in a minimally invasive manner without pain, discomfort, or significant risk to the patient, that is, that nutrition is rudimentary medical and nursing care. Other medically oriented literature implies that provision of TPN upholds the dignity of the patient whilst enhancing the trust and confidence imperative to the physician-patient relationship (Ashby and Stoffell 1995; Craig 1994; Studebaker 1988). Likewise, it has been argued that nutrition (parenteral, enteral or oral) is equivalent to, or the same as 'food on the table' which has immense emotional and symbolic importance as being part of the most basic bond that exists between two persons from the moment of birth onwards (Mayo 1996; Sanstead 1990). All of these arguments point generally toward a final reasoning that surrogate decision makers cannot ethically waive the provision of TPN, because this treatment is so basic.

Another argument for the provision of parenteral feeding has to do with hope. Turco (1998) explains that hope is vitally important to human existence, and without it, advanced cancer patients may experience hopelessness, helplessness and despair. Hope encourages and energizes people and protects them from being swallowed up by suffering and negativity.

In Margaret's case, the provision of home TPN was in many ways associated with the hope that the treatment would enhance her quality of remaining life. It is this notion of hope, however, that leads us to the arguments against the continued burdensome provision of TPN in the advanced cancer patient. The reliance on hope can also be criticised from an ethical viewpoint. We must question if it is at all ethical to bestow false hope on to a patient with terminal cancer by implementing or continuing TPN treatment, and not acknowledging the reality of the person in receipt of care. Indeed, as Margaret asks us, for whom are we providing such treatment, and we might even ask who is doing the hoping?

Arguments against TPN in cancer therapy

Dunlop et al (1995) argue that there is no clear evidence that increased nutritional support such as TPN alters comfort, mental status or survival of patients who are dying. Some of the arguments in support of the continuation of TPN can be disputed by the information derived from individual cases, whereas others have been addressed on a broader level. Mayo (1996) argues that TPN is equivalent to other forms of life-supporting care and can be forgone on the same basis as ventilation and dialysis, for example. This reasoning reflects the movement of some ethicists away from the idea that 'ordinary care' and extraordinary care' are at all times meaningful distinctions. For example, life-supporting treatment enhances an essential body function that the patient cannot adequately provide independently. This view suggests, for example, that ventilators provide a delivery system for respiration.

Complex vascular access devices inserted for the delivery of TPN provide nutrition, fluid, and blood products, nothing more and nothing less. More candidly, air to breath and food to eat might read as being 'basic'. However parenteral nutritional support, which requires a surgically invasive procedure, is hardly 'basic' or non-invasive. The numerous risks associated with long term TPN, as well as the discomfort, cannot be disregarded as inconsequential or trivial. Few would equate it with the human dimensions of unassisted eating. Furthermore, patients and their families may well consider the provision of this level of complex invasive care as achieving exactly the opposite of what they are trying to achieve.

Some authors suggest that, despite TPN not being useful for the majority of advanced cancer patients, there is a small subset that may gain benefit (Dunlop et al 1995). Margaret clearly continued to deteriorate, encountering morbidity associated with treatment. Yet she did derive nutritional benefit from home TPN, albeit minimal, in that she maintained her weight although at a level less than an optimal body weight. Fainsinger and Gramlich (1997) similarly maintain that there is clear evidence that the majority of advanced cancer patients derive minimal nutritional benefit via the use of TPN. However, there is agreement that a specific group of highly selected patients do benefit nutritionally. Yet, as with Margaret, such gains involve considerable complications and have clear implications for quality of life.

Within the Western literature, there is a clear consensus on the rights of people to refuse treatment. Mercadante (1995) warns that it is not possible to avoid the influence of the patient's and family's values, personal beliefs, and attitudes when making a decision about withholding or continuing home TPN. The difficulty in estimating life expectancy, and therefore predicting the benefits of treatment, means that patients' desires about therapeutic choices must be given consideration even if the attitude of the health care team members is not in favour of such aggressive treatment.

Resources

Health service managers exert ever-increasing influence on medical treatment (in home and hospital settings) in an attempt to contain costs. Endorsing the provision of home TPN based on cost raises some interesting issues, displaying the economic dimension to ethical decision making, especially in terms of resource allocation. The North American literature suggests that continuation of such treatment could be a revenue generating exercise that fits comfortably (technically speaking) into the reimbursement/prospective payment model of health care provision payment (Quillan 1998).

In the Australian context of public health care, this concept does not apply, although some variations on a communitarian theme exist in outsourcing of health care by public providers. In the vast majority of Australian situations no revenue is generated by the provision of artificial nutritional support. A few exceptions are associated with private providers of health care, which is an expanding phenomenon given the Federal Governments policy thrust of promoting enrolment in private health insurance.

Macfie (1996) recognises that resource allocation implications will be enormous if all patients in those categories of malnutrition (as defined by the American Society of Enteral and Parenteral Nutrition Guidelines 1993) are to receive nutritional support. This would inevitably lead to some conflicts between clinicians and management personnel. Nonetheless, there is no precedent that deems that resources should be seen as a reason not to treat. This dichotomy represents an ethical minefield - one that can hardly be the focus of this paper.

Those with experience in caring for patients with advanced cancer acknowledge that it is unusual for patients and families to request or insist upon TPN when they have been advised of its negligible medical benefits (Fainsinger and Gramlich 1997). Nonetheless, one would hope that a health care system, regardless of its spatial location, would grant adequate flexibility so that patients and their families/carers could make their own decisions regarding the provision of invasive treatments such as parenteral feeding. It is not unreasonable to ask whether this collaboration between the consumers and providers would be significantly challenged in times of severe budgetary constraint? Australia's current health budget deficit is no exception and indeed, the difference in power between patient and provider provides significant challenges to the provision of an equitable dialogue, as Margaret's narrative shows.

Margaret's narrative helps us to focus on the experience of patients as being vital, not only in making individual treatment decisions but in establishing policy which sees *quality* and *ethics* from a consumer perspective. This is not a case of being pro or anti TPN but recognising that individual case studies are located within powerful institutional and personal settings. Narrative helps us to

understand those contexts and to understand the notions of *appropriate* and *inappropriate* care as being context specific, whilst understanding the socio-political dimensions of care.

Quality of life

Health care professionals frequently employ the term *quality of life*, yet it is a complex abstraction that lacks shared definition, resulting in inconsistencies in its interpretation (Goodhall 1997). It is often a term that is inappropriately used at the bedside, being represented as an objectified reality. The question of how to define quality of life is complex and as Johnstone (1989) suggests, might never find a satisfactory answer. The acknowledgement that quality of life is overwhelmingly subjective is important. Just as important is the recognition that quality of life is also multi-dimensional, with both subjective and objective components (Meeberg 1993).

In reality, it is difficult for others to understand a person's quality of life without critically appreciating the way our own value systems can operate to mediate or even outweigh the beliefs, feelings, wants, needs and aspirations of patients. More importantly, when making decisions for non-autonomous people their subjective component is clearly missing, necessitating onlookers to draw on their own values, thus challenging us to think critically about our notions of quality of life in others. Margaret on the contrary was completely autonomous, and fully cognisant of that fact that she did not possess the freedom to enjoy a quality life, as defined by her. In Margaret's case, home TPN afforded prolongation of life that lacked quality and indeed created burden disproportionate to the benefit.

Encountering ethical perspectives

Conflicting ethical viewpoints are often encountered in making clinical decisions regarding withholding and withdrawing parenteral feeding for advanced cancer patients. One of the issues is to be found in the way in which dilemmas are defined in accordance with the norms of the biomedical model. The view that medical and nursing professions have differing ethical foci is well supported in the literature (Goodhall 1997; Tchudin 1992; Tingle and Cribb 1995). Johnstone (1989) suggests that nurses are continually advised by medical practitioners that nursing practice is devoid of any sort of moral complication and that it is nonsense for nurses to assume they have any independent moral responsibilities when caring for patients. Yet, this sweeping statement can hardly be sustained. Nurses must be permitted to identify and fulfill their ethical responsibilities when delivering nursing care, and cannot be expected to ignore or violate these. If nurses were to play a more active role in ethical decision-making, a complementary balance of the two ethical orientations might be accomplished.

Unfortunately, our experience was not based on such a complementary or collaborative approach to decision

making. As a result, this decision-making process was not characterised by the health care professionals having respect for the patient's autonomy, to cause her no harm, to engender benefit, and to consider the interests of her family. Although such an approach is hardly optimal, it is in reality common practice, reflecting the dominant power relationships. Medical practitioners dominate and can even define what constitutes 'the ethical decision making process', resulting in an imbalance which fosters a paternalistic biomedical ethic. This imbalance could be redressed by nurses, and is slowly being addressed by nurses, but it requires us to find the courage and systemic support to take a more active role in ethical decision-making. Nurses may well not be legally empowered to have such a role but in terms of ethics clearly have a responsibility. Here the resolution of such a dilemma requires attention to power dynamics and communication practices by all within the health care team, including ensuring that patient advocacy perspectives are fostered.

CONCLUSION

Despite an extensive literature search, no randomised controlled trials were located in the area of forgoing parenteral feeding in the patient with advanced cancer. Although this topic is highly contentious, we should not be afraid to care for individuals according to the ideals of palliative care, where control of symptoms, not normalizing of physiological parameters, is the fundamental obligation.

Inspired by an attitude of respect for a good life and death, we have suggested that it is feasible to consider, as a general guideline, that the provision of home TPN should be gradually decreased when it has been determined that a patient has reached the terminal stage, or is in an irreversible deteriorating process, or when the TPN is the cause of additional complications and suffering, or when this action is requested by the individual on the receiving end. Many nurses know the experience of inappropriate or disproportionately burdensome provision of life-prolonging treatment, which only exacerbates a person's suffering. Yet we all know how hard it is to stop providing the treatment. However, the very 'winding down' of aggressive intervention can symbolise an approach to care that goes beyond the medical model, inviting dying patients to begin their final journey and giving us, their health care providers, the chance to take part in their inner dialogues and to offer support. In the discourse of palliation this is all well and good to accept. Yet it does not make the decision making process any easier when confronted with the ethical dilemma of seeking justification of long term parenteral feeding - its use, its cost and whether or not it is wanted by the recipient.

Developments in medical knowledge and technology enable the health care profession to employ greater control

over life and death. However, being able to prolong life in some cases may be in conflict with the ethos of caring, which has as its core empathy for others and relief of suffering. As was our experience with Margaret, inappropriate home TPN can further reduce quality of life through additional pain and discomfort, perceptions of loss of dignity and ensuing complications. That which constitutes appropriate and inappropriate TPN will of course vary from case to case.

This case study undoubtedly challenges us to think beyond automatic assumptions that we must never withhold the basic necessity of food, challenging us to think again about what constitutes food and care in particular circumstances. It is therefore representative of a quandary for those involved in decision-making regarding: to feed or not to feed. These are the continuing ethical dilemmas associated with determining the appropriate path between overtreatment and neglect. As Margaret's case narrative teaches us, not only is the process difficult, but we are challenged to reflect critically upon the following: what do we do in the name of care; whose knowledge counts; and, who are we really treating with TPN in a variety of circumstances?

REFERENCES

- Ashby, M. and Stoffell, B. 1995. Artificial hydration and alimentation at the end of life: A reply to Craig. *Journal of Medical Ethics*. 21(3):135-40.
- Bozetti, F. 1989. Effects of artificial nutrition on the nutritional status of cancer patients. *Journal of Parenteral and Enteral Nutrition*. 13(4):406-420.
- Craig, G. 1996. On withholding artificial hydration and nutrition from terminally ill sedated patients. The debate continues. *Journal of Medical Ethics*. 22(3): 147-153.
- Curtin, L. 1994. Ethical concerns of nutritional life support. *Nursing Management*. 25(1):14-16.
- Daly, J.M., Hoffman, K. and Lieberman, M. 1990. Nutritional support in the cancer patient. *Journal of Parenteral and Enteral Nutrition*. 14(Suppl 5): 100s-105s.
- De Wys, W.E., Begg, C. and Lavin, P. 1980. Prognostic effects of weight loss prior to chemotherapy in cancer patients. *American Journal of Medicine*. 69(4): 491-497.
- Duff, R.S. 1987. Close-up vs distant ethics: Deciding the care of infants with poor prognosis. *Seminars in Perinatology*. 11(3): 244-253.
- Dunlop, R.J., Ellershaw, J.E., Baines, M.J., Sykes, N. and Saunders, C.M. 1995. On withholding nutrition and hydration in the terminally ill: Has palliative medicine gone too far? A reply. *Journal of Medical Ethics*. 21(3):141-143.
- Fainsinger, R.L. and Gramlich, L.M. 1997. How often can we justify parenteral nutrition in terminally ill cancer patients? *Journal of Palliative Care*. 13(1):48-51.
- Fawcett, H. 1993. Interpreting a moral right: Ethical dilemmas in nutritional support for terminally ill patients. *Professional Nurse*. 8(6):380-383.
- Goodhall, L. 1997. Tube feeding dilemmas: Can artificial nutrition and hydration be legally or ethically withheld or withdrawn? *Journal of Advanced Nursing*. 25(2):217-222.
- Grant, J. 1990. Supplement. *Nutrition*. 6(4):6.
- Guidelines for the use of parenteral and enteral nutrition in adults and pediatric patients. 1993. *Journal of Parenteral and Enteral Nutrition*. 17(Suppl):5A.
- Latimer, E. 1991. Caring for seriously ill and dying patients: Philosophy and ethics. *Canadian Medical Association Journal*. 144(7):859-864.
- Johnstone, M.J. 1989. *Bioethics - A nursing perspective*. Marrickville. Harcourt Brace Jovanovich.
- Macfie, J. 1996. Ethical implications of recognizing nutritional support as a medical therapy. *British Journal of Surgery*. 83:1567-1568.

Mayo, T.W. 1996. Forgoing artificial nutrition and hydration: Legal and ethical considerations. *Nutrition in Clinical Practice*. 11(6):254-264.

Meeberg, G.A. 1993. Quality of life: a concept analysis. *Journal of Advanced Nursing*. 18(1):32-38.

Mercadante, S. 1995. Parenteral nutrition at home in advanced cancer patients. *Journal of Pain and Symptom Management*. 10(6):476-480.

Philip, J. and Depczynski, B. 1997. The role of total parenteral nutrition for patients with irreversible bowel obstruction secondary to gynecological malignancy. *Journal of Pain and Symptom Management*. 13(2):104-111.

Quillan, P. 1998. *Nutrition in Cancer Treatment*: www.healthy.net/hwlibraryarticles/quillin/technica.html.

Sandstead, H. 1990. A point of view: Nutrition and care of terminally ill patients. *American Journal of Clinical Nutrition*. 52(5):767-9.

Shaw, C. 1992. Nutritional aspects of advanced cancer. *Palliative Medicine*. 6:105-110.

Studebaker, M. 1988. The ethics of artificial feeding (Letters to the Editor). *The New England Journal of Medicine*. 319(5):306.

Tchekmedyan, N.S. 1993. Clinical approaches to nutritional support in cancer. *Current Opinion in Oncology*. 5(4):633-638.

Tingle, J. and Cribb, A. 1995. *Nursing Law and Ethics*. Oxford: Blackwell Science.

Tschudin, V. 1992. *Ethics and Nursing (edn)*. Oxford: Butterworth-Heinemann.

Watts, D. and Cassell, C. 1984. Extraordinary nutritional support: A case study and ethical analysis. *Journal of the American Geriatrics Society*. 32(3):237-242.

Turco, S. 1998. *What's hope got to do with it?* Edmonton Palliative Care Program. Canada: Capital Health Authority.

INTERNET-BASED EDUCATION FOR ENROLLED NURSES: COULD IT BE E-FEFFECTIVE?

Tanya Field, RN, ICU Cert, Grad Dip FET, MEd, is Lecturer in the School of Human Services, Department of Arts, Multimedia and Human Services, Victoria University of Technology, Sunbury, Victoria, Australia

Accepted for publication September 2001

Key words: nurse education, Internet, enrolled nurses, multimedia, computer-assisted instruction

ABSTRACT

There has been an extraordinary growth of technology-mediated learning in the higher education system over the last 10 years (IHEP 2000, p.1), predominantly in the area of distance education. These technological advances provide exciting opportunities for the delivery of education to those who have not previously been able to access on-campus learning, usually because of barriers of distance and cost.

While there are a growing number of studies supporting the implementation of distance education programs in nursing education, the use of Internet-based learning as a sole means of education delivery is relatively new. This paper investigates the current literature available regarding the use of Internet-based education delivery for registered and enrolled nurses in undergraduate and postgraduate programs, and reviews contemporary education trends in Victoria, Australia, for enrolled nurses (ENs).

The challenge in nursing education currently is to design curricula that will address the health care needs of the future. This is not easy with the rapidly changing environment health care professionals, especially nurses, face in their daily work. To prepare graduates who can function successfully as professional nurses in this new century, nurse educators must examine the dominant trends in health care and education, and analyse whether the processes used to prepare students for practice will result in the desired outcome (Jorgensen et al 1998, p.109). The current growth and impact of web-based and online learning courses has been proposed by some as a major revolution for education, and has been firmly embraced by many tertiary institutions as the way of the future (Sims 1998, p.21).

INTRODUCTION

Quality education is a universal goal held by most within the teaching profession. It is common to hear arguments that instructional technology will be the key to educational quality as we progress through this millennium. A number of enthusiasts of educational technology believe that quality has and will continue to increase rapidly, creating a new educational culture (Garson 2001, p.1). Sims (1998) argues that the majority of self-paced online learning applications tend to reflect the naivety of the developer rather than demonstrating sound theoretical frameworks. So where does this leave nursing education and the question of the effectiveness of Internet-based learning for ENs?

APPROACHES TO DISTANCE EDUCATION

There are a number of articles describing the different approaches to distance education for nurses (Garson 2001; Loving and Wilson 1999; Clarke 1998; Ribbons 1998; Sheppard and Mackintosh 1998; Lewis, Watson and Newfield 1997; Blue and Howe-Adams 1993). Many of these focus on a paper-based curriculum predominantly in the graduate sector, but there are increasing numbers which discuss incorporating online learning into their nursing programs. It is worth considering these papers in the context of developing a curriculum for undergraduate education, which incorporates a distance education and/or online format for nurses. At this time there is minimal literature that discusses EN education, let alone education provided to them via distance education or the Internet.

Distance learning is not a new concept. It has been around in some form for over 150 years, but only a small number of nursing schools in Australia have offered distance education courses for more than 10 years (Reinert and Fryback 1997, p.421). Despite the popularity of off-campus courses in other disciplines, a number of schools of nursing have been reluctant to incorporate this methodology into their curriculum. Contemporary tertiary nursing institutions must respond to a number of challenges, such as the need for advanced practice nurses, rural nurses, and a cost-constrained environment, which

affect the retention of quality academic staff (Reinert and Fryback 1997, p.422). In view of this, distance education technologies, especially online delivery, are being examined for their suitability for nursing education, in both undergraduate and postgraduate programs. Cragg (1991) asserts that distance education provides an efficient means of reaching nurses separated from educational institutions by geography or other circumstances that make face-to-face instruction difficult (Cragg 1991, p.256). Whether the focus is on undergraduate, graduate or continuing education, there is need to meet the educational demands of nurse learners struggling to fit within the changing health environment (Sherwood et al 1994, p.251).

Viverais-Dresler and Kutschke (1992), in a study of registered nurse (RN) students in a baccalaureate program, found nursing skills are best learned when the student can test theory and beliefs in a practice setting (Viversais-Dresler and Kutschke 1992, p.224). This has serious implications for distance education and the online delivery of nursing education. Sims (2000) believes the shift to technology-based and online learning has increased the focus on learners and learning through a student-centred approach to curriculum development.

As tertiary institutions rely more on the online delivery and access of their courses, there is an increase in the expectations of an independent, often geographically isolated, learner to use those materials effectively (Sims 2000, p.22). But is this asking too much of an undergraduate student with limited knowledge and skills in both their chosen field and potentially the computer technology used to deliver the course?

TECHNOLOGY OR LEARNING?

Bechervaise (2001) stresses with online technology educators must consider the questions: 'What comes first - the technology or the learning? Which is the driving force? He sees the role of education as teaching people how to learn and that the 'magic' happens when the teaching style matches the learning style. Learning is individual and non-linear, so how does this fit with online delivery? Sims (2000) believes that producing materials for online delivery is not about 'creating nice-looking digital paper, but of harnessing the potential that online environments can provide through employing new methods of information and visual communication' (Sims 2000, p.22). Clarke and James (1997) see the purpose of flexible, including online, learning as improving educational quality, specifically in relation to improving access, availability, relevance, and the way in which the individuals' needs and the needs of stakeholders (that is, employers, providers and validating bodies) are met (Clarke and James 1997, p.1243).

Sheppard and Mackintosh (1998) propose that recent technological advances provide exciting opportunities for the delivery of education to rural and remote health professionals as they overcome the barriers of distance and

cost, and create a learning environment that maximises interactivity and develops information literacy. Whilst they focus predominantly on postgraduate education they believe that undergraduate training provides the foundations of disciplinary knowledge and skills, and this is vital in fostering a commitment to ongoing learning. They assert that the different nature of rural and remote area health care to metropolitan service delivery requires unique education that is specific to the needs of rural professionals (Sheppard and Mackintosh, 1998, p.189). Blue and Howe-Adams (1993) argue that rural and remote health professionals require diversity, flexibility and recognition of individual and local education needs in the structure and content of the courses of learning they undertake (Blue and Howe-Adams 1993, p.7). For nurse educators this is an important consideration when developing curricula that meet the needs of those who use them. Do our current means of educating rural and remote area ENs provide them with the knowledge and skills to function competently within the communities where they will work?

MAINTAINING A LEARNING CENTRED APPROACH

While in essence George and Gibbins (1999) support online learning, they argue that if we are to maintain a learner-centred approach for rural health workers living in rural and remote areas what is needed is a diversity of delivery methods, utilising a range of technologies, to respond to the diversity of the environment. Computer-mediated communication is gaining momentum in this new millennium, however, solely focusing on Internet-based learning can deprive many of the chance to undertake professional education. This also highlights equity and access issues for rural and remote area students. As Blue and Howe-Adams discuss, the issues for those in rural and remote areas are those of choosing a suitable education program, accessing that program, and actually staying in the program, which for those involved can be a daunting task (Blue and Howe-Adams 1993, p.7).

Technology can be one solution to some teaching and learning situations which require flexibility. George and Gibbins (1999) found, in their study of the effectiveness of distance education delivery methods, that rural health workers, although keen to use technology, can quite often be disadvantaged because of access problems. The study also found that online delivery did not score well in the survey of preferred delivery modes, and when looking at access to facilities and confidence levels, only 9% of respondents had continuous access to email and Internet, and 60% had no access at all to either email or the Internet (George and Gibbins 1999). This finding is supported by Stillman (2001) who also found that rural and remote users needed sites that were quick and easy to use, both technically and in their design. When downloading information more than 55% can only operate at 14.4 kilobytes/second, and 30% at

9.6 kilobytes/second. Interestingly, Stillman estimates that more than 30% of rural users keep images turned off because of the difficulties of access and download time. This finding has important implications in various nursing subjects that may require the use of imagery to allow effective learning to occur.

PRACTICALITIES OF ONLINE EDUCATION

The Tasmanian School of Nursing, in Australia, undertook online teaching in 1996 as an initiative towards the better delivery of nurse education in that State, particularly for rural and remote area access. They used two subjects in their bachelor of nursing program, which was available to both RN and EN students. A profile of student respondents showed that the majority were female ENs, studying in Launceston, and aged between 27-40 years. The findings of the study indicated that many students enjoyed the format and delivery, and although they experienced some difficulties, they found their electronic skills improved over the semester and that they benefited from the experience (Martyr 1998, p.10).

In contrast to George and Gibbing's findings, the majority of students in this program used home computers followed by the nursing computer laboratory, indicating that access was not an insurmountable issue for them. Given that the majority of participants were EN students, this indicates that these students were keen to further their professional development via online delivery methods.

The author's review of EN (Division 2) nurse education providers in Victoria, Australia, found that there was limited use of online technologies within these programs (Field 2001). A number of the providers used Internet-based resources as part of the course but no subjects were taught solely online.

The use of email was encouraged as a means of communication between student and lecturer, and in one program a web site has been set up for self-directed learning in medical terminology to support the anatomy and physiology component of the course. Another provider used Internet access in the 'directed study' time to enable students to develop their Internet skills and complete assignments. It was felt that these students would not cope with 100% online content straight off, but after the first semester they would have the skills to manage their learning by this means of delivery. The rationale given was that the teachers have found they need to wean the students out of 'learned helplessness'.

The profile of a student undertaking EN studies in a number of tertiary institutions in Victoria is that of a mature aged female, average age 30, who is generally not confident in her computer skills or the ability to learn in the initial stages of the course (Field 2001).

In comparison to the Tasmanian experience, this reflects a similar result if one takes into account that in the first year of study in Tasmania the students undertook a

subject on applied computing. Thus, for the Victorian students once they had gained the knowledge, skills and comfort in using the technology the results were very positive, with students achieving higher than expected grades (Field 2001). Therefore, the use of online technology has a place in the education of ENs to improve learning outcomes. But how can we do this successfully and achieve the best result for the student, especially those in rural and remote areas?

INTERNET BASED EDUCATION: THE FUTURE

McGonigle and Mastrian (1998) assert that online teaching will continue to move to the forefront and reshape education as we know it today, with an increasing number of nursing courses delivered, either in part or totally, over the World Wide Web. They believe that improved student user preparation will lead to enhanced student learning in this new educational environment, and that students must be prepared for a major adjustment in their educational structure. It is imperative that students are comfortable in the new learning environment developed for them (McGonigle and Mastrian 1998, p.81). This view confirms the findings outlined above where ENs achieved excellent results in their studies once they were comfortable with the delivery technology. Rose et al (2000) found students required at least a two hour orientation which included an overview of course requirements, the course components, and directions for using the web browser, email and discussion boards in their online graduate epidemiology course (Rose et al 2000, p.163). While these recommendations about student use are important, it is necessary that for online learning to be successful teachers also need to have a sound understanding of the technology and learning approaches required in this delivery mode.

The ability of digital-based technology to deliver text, full colour graphics, sound, video, and animation on one platform provides nurse educators with a tool unrivalled in its capacity to enhance the teaching and learning process. Ribbons (1998) states that one of the most important characteristics of multimedia technology is its ability to offer an enjoyable, effective and flexible method of instructional delivery which attracts the learner's interest, maintains attention, and accommodates a diversity of learning styles (Ribbons 1998, p.109). Clark (1998) argues that introducing nursing students to the Internet and computer technology is fundamental in educating the nurse for the future, and in addition, the Internet should be used in the nursing classroom as a resource to supplement teaching materials. She describes the benefits of developing a web site in an undergraduate nursing program for the purpose of providing a resource for further study and research relevant to the course, and the integration of a web site evaluation tool to assist students in thinking critically about nursing resources available on the Internet.

This new educational concept allowed participating students to learn how to use a computer, email and the Internet to locate professional information, and enabled the nursing students to gain a broader perspective of the profession (Clark 1998, p.220).

DESIGN OF INTERNET-BASED EDUCATION

The process of designing an effective Internet-based course requires faculty commitment, administrative and technical support, and financial resources. An important factor to consider when planning the integration of online technology as a method of course delivery is the conceptual approach to the curriculum (Carlton et al 1998, p.48). Review of the classroom content for its applicability to online delivery is essential when designing an Internet course. A number of studies recommend that it is vital that a team approach is taken and that time is allowed to develop the materials to ensure relevance and suitability to an online environment (Carlton et al 1998; Clark 1998; Ribbons 1998). While considerable amounts of time and expense will occur in the development of a quality online course, Rose et al (2000) assert that each subsequent time the course is offered, operating costs should decrease significantly for faculty, the system support and database administration (Rose et al 2000, p.163). This is an important factor when tertiary institutions are receiving less funding, and yet still are expected to produce quality courses and graduates.

IMPLEMENTATION ISSUES

Lewis et al (1997) identify some difficulties encountered in implementing technology in academic settings. These include the age of the faculty and administrators, a general lack of understanding of the potential of the technology to support instruction, and a lack of funds for hardware and software acquisition. Other concerns faced by faculty may include a perceived threat to traditional faculty roles, fear of loss of employment, and a perceived inability to control the teaching process. They found that nursing faculty in particular felt that computers potentially interrupted the interpersonal relationships with students and patients that are central to building caring, therapeutic relationships (Lewis et al 1997, p.188). This view is disputed in a number of articles in their evaluation of online programs in nursing. Evaluation of these programs found that there was a high level of interaction and relationship development among students and between students and faculty when participating in online programs and that extra time was often required at the end of the course for exchange of contacts (Baier and Mueggenburg 2001, p.3; Rosenlund and Damask-Bembenek 1999, p.5).

Nurse educators have traditionally used a didactic model to deliver instruction in the classroom and this may explain some fear regarding the implementation of

Internet learning. A prominent feature of this traditional educational philosophy is a hierarchical view of teacher and students - faculty teach, students learn.

An alternative philosophical view is that faculty has a responsibility to provide the structure within which students can learn independently and collaboratively (Loving and Wilson 2000, p.70). It is this latter view that will allow academics to incorporate new technology into their teaching and facilitate the development of independent critical thinking abilities within their students.

Computer-assisted instructional programs are one way of helping students achieve this independence. The implementation of virtual reality and interactive multimedia programs have proven to be successful in communicating educational objectives and involving the student as an active participant in the learning process (Rouse 1999, p.172; Hodson Carlton 1996, p.148). Oliver (1999) discusses the development of a multimedia CD-ROM which presents a virtual reality hospital ward to help prepare final year nursing students for entry into the workforce. By simulating the every day complexities of clinical decision-making the multimedia courseware seeks to make the education of nursing students as authentic as possible (Oliver 1999, p.16).

CONCLUSION

The use of the Internet and online courses has great potential for improving the education and learning outcomes for ENs. It is vital that providers of this education seek new and innovative ways to present their courses, which increase access and opportunity for students throughout Australia. Sadly in an online education report, White (1999) identifies that TAFE institutions have the lowest number of student online users in Australia (White 1999, p.3). If TAFE and other providers wish to continue their commitment to providing quality education to ENs, especially in rural and remote areas, they need to consider the technologies available and the integration of multimedia and online delivery methods into their programs to enhance the learning process for their students.

REFERENCES

- Baier, M. and Mueggenburg, K. 2001. Using the Internet for clinical instruction. *Nurse Educator*. 26(1):3.
- Bechervaise, N. 2001. *Electrifying lecture notes: Online delivery and educational opportunity*. Paper presented at the Australian Education Assembly 2001. April 19. Melbourne. Australia.
- Blue, I. and Howe-Adams, J. 1993. Education choices: A program of educational support for multidisciplinary health professionals in rural and remote areas. *The Australian Journal of Rural Health*. 1(3):7-15.
- Carlton, K.H., Ryan, M.E. and Siktberg, L.L. 1998. Designing courses for the Internet: A Conceptual Approach. *Nurse Educator*. 23(3):45-50.
- Clark, D. 1998. Course redesign: Incorporating an Internet web site into an existing nursing class. *Computers in Nursing*. 16(4):219-222.
- Clarke, B. and James, C. 1997. The purpose of flexible learning in post-registration nurse education. *Journal of Advanced Nursing*. 26:1243-1251.

- Cragg, C.E. 1991. Professional resocialization of post-RN baccalaureate students by distance education. *Journal of Nursing Education*. 30(6):256-260.
- Daly, J.M., McClelland, E. and Yang, J. 1994. The effect of teaching via telecommunications: A comparison of the academic performance of RN-BSN students in satellite centers and on campus. *Journal of Nursing Education*. 33(4):172-174.
- Field, T.D. 2001. Email correspondence with Victorian Division 2 nurse providers. Sunbury, Australia. June 6.
- Garson, G.D. 2001. *The role of technology in quality education*. North Carolina State University. Downloaded 02/06/01: David_Garson@ncsu.edu.
- George, M. and Gibbings, B. 1999. Distance education and training can be like making a chocolate cake - finding the right blend. Distance and Open Learning Conference. Adelaide, Australia.
- Hodson Carlton, K.E. 1996. Implications for nursing education: A virtual Mrs Chase and Cyberspace. *Computers in Nursing*. 14(3):148-149.
- Jorgensen Huston, C. and Fox, S. 1998. The changing health care market: Implications for nursing education in the coming decade. *Nursing Outlook*. 46(3):109-114.
- Lewis, D., Watson, J.E. and Newfield, S. 1997. Implementing instructional technology: strategies for success. *Computers in Nursing*. 15(4):187-190.
- Loving, G.L. and Wilson, J.S. 2000. Infusing critical thinking into the nursing curriculum through faculty development. *Nurse Educator*. 25(2):70-75.
- Martyr, P.J. 1998. Teaching a bachelor of nursing unit online: Some experiences and results. *Australian Electronic Journal of Nursing Education*. 3(2):1-13.
- McGonigle, D. and Mastrian, K. 1998. Learning along the way: Cyberspatial quests. *Nursing Outlook*. 46(2):81-86.
- Oliver, M. 1999. Virtual hospital gives graduates 'real' skills. *Nursing Review*. July 1999. 16.
- Reinert, B.R. and Fryback, P.B. 1997. Distance learning and nursing education. *Journal of Nursing Education*. 36(9):421-427.
- Ribbons, R. 1998. Guidelines for developing interactive multimedia: Applications in nurse education. *Computers in Nursing*. 16(2):109-114.
- Rose, M., Frisby, A.J., Hamlin, M.D. and Jones, S. 2000. Evaluation of the effectiveness of a web-based graduate epidemiology course. *Computers in Nursing*. (4):162-167.
- Rosenlund, C.H. and Damask-Bembenek, B. 1999. Assessing the effectiveness of an online program. *Nurse Educator*. 24(1):5-6.
- Rouse, D.P. 1999. Creating an interactive multimedia computer-assisted instruction program. *Computers in Nursing*. 17(4):171-176.
- Sheppard, L. and Mackintosh, S. 1998. Technology in education: What is appropriate for rural and remote allied health professionals? *Australian Journal of Rural Health*. 6:189-193.
- Sherwood, G.D., Armstrong, M.L. and Bond, M.L. 1994. Distance education programs: Defining issues of assessment, accessibility and accommodation. *The Journal of Continuing Education in Nursing*. 25(6):251-257.
- Sims, R. 1998. Technological determinism or educational effectiveness? *Australian Journal of Advanced Nursing*. 16(1):21.
- Sims, R. 2000. On-line alchemy: Preventing gold being turned into lead. *Australian Journal of Advanced Nursing*. 18(1):22.
- Stillman, L. 2001. Who can use e-learning?: Issues of access and equity to the equipment and delivery systems. E-learning: Ethics and Equity Conference. Victoria University. Melbourne, Australia.
- The Institute for Higher Education Policy. 2000. *Quality on the line: Benchmarks for success in Internet-based education*. IHEP. Washington.
- Viverais-Dresler, G. and Kutschke, M. 1992. RN students: Satisfaction with clinical teaching in a distance education program. *The Journal of Continuing Education in Nursing*. 23(5):224-230.
- White, G. 1999. *Online education report*. Downloaded 02/06/01: <http://www.edna.edu.au/EdNA/>.

THE PARTICIPATION OF VOLUNTEERS IN CONTEMPORARY PALLIATIVE CARE

Margaret M. McKinnon, RN, BA, MEdSt, is currently a volunteer with hospice and palliative care agencies

Accepted for publication April 2002

Key words: volunteering, palliative care volunteers, palliative care, death and dying

ABSTRACT

Historically, in Australia, individuals with widely differing interests, skills and values have engaged collaboratively, in a voluntary capacity, to establish services to assist persons experiencing particular need or hardship. Gradual recognition and acceptance by the State of its social responsibilities to citizens with various needs in areas of health, welfare, education and others, have seen the provision of a range of statutory services available to all Australians. Volunteer participation in the delivery of modern health services, therefore, is not usual; palliative care is an exception rather than a norm.

This article explores the relationship between understandings of death and dying in Western culture and the participation of volunteers in contemporary palliative care. The author presents a view that volunteers provide a distinctive contribution to the quality of care delivery and to enrichment of the social environment of the wider community also. The topic is of relevance to all nurses and especially those involved in the care of dying persons and of their families.

INTRODUCTION

Until the second half of the 20th century in Australia, most terminally ill patients were cared for at home and died there. A small number only of hospices conducted by Catholic and Anglican communities offered care and support exclusively to dying patients and to their families (Redpath 1998). In subsequent decades, persons dying of life-threatening illnesses were cared for in acute hospitals where the ideas and ethos under-lying services gave emphasis and priority to those interventions directed towards prolonging life and eradicating disease.

Patients whose illness was unresponsive to medical interventions received limited information as to their health status and the choices open to them in relation to care (Redpath 1998; Kasap et al 1997). Most patients admitted to acute care institutions died there. Nevertheless, some people expressed a preference to die at home (Kingsbury 1980). During the 1980s, a variety of community-based programs, offering alternative approaches to care of dying persons emerged across the country. Financed, in the main, by charitable and/ or non-profit organisations, such programs gave visibility to the independent and varied efforts of individuals and groups (both lay and professional) who sought to bring about change in the care of patients living with terminal illness (Redpath 1998; Elsey 1998).

Since 1989, the Australian Federal Government has provided monies for a range of palliative care programs in all States and Territories of Australia.

'Palliative care' is defined as 'specialised health care of dying people aiming to maximise quality of life, and assist families and carers during and after death' (Palliative Care Australia 1999, p.v). A common feature of contemporary models of service delivery in Australia is the participation of volunteers in care programs, where appropriate. The inclusion of 'non-professional' volunteers as care team members directs attention to considerations of social attitudes towards the phenomenon of death and the care of dying persons and their families (however defined). What do volunteers offer when caring for vulnerable and dying persons?

This paper explores understandings of death and dying in Western society and elements of volunteering, using selected theoretical and philosophical assumptions and research findings, where available. Approaches to hospice/palliative care are outlined and are used to provide a context for discussion of aspects of volunteer involvement in contemporary palliative care and what volunteers may offer patients and society generally. No attempt is made to consider the economics of volunteer participation in care programs.

Death and dying in contemporary Western culture

In itself, death is a mystery. Our attempts as embodied beings to conceptualise our own death in terms of non-being, non-existence or nothingness are futile and nonsensical (Bury 1997, Bauman 1992). Yet the meanings of death to individuals and communities are profound. The unfathomable nature of mortality and its inevitability, commonly provoke feelings of anxiety, fear and insecurity and challenge the meaningfulness of human life. Each culture handles the actuality of death, of dying and of living in its particular way, constructing its own sets of meanings, belief systems and patterns of social activity which seek to ensure ontological security of individuals and continuing social stability of communities (Giddens 1991).

In his study and analysis of Western attitudes to death from the 1400s until the 1970s, Ariés (1981) postulates a series of models to describe changes in meanings of death and associated events which occurred over that period, situating each model in the context of alterations in the prevailing world view and its underlying ideologies, beliefs and systems of thought. Ariés (1981, p.28) claims that in earlier times, that is, prior to the 15th century, dying was perceived as another event in the natural order and humankind's destiny. Death and rituals associated with it were of public concern; a shared and 'resigned' approach to death, he asserts, tamed its meanings. The model of the 'tamed death' contrasts markedly with that which Ariés identifies in modern culture, where he maintains, death is perceived as an 'invisible', silent event controlled by technologies (Ariés 1981, pp.611-612).

Stoddard (1992, p.223), suggests that issues surrounding death, trauma, and bereavement are discussed more openly today and that members of society have integrated these concepts within the reality of their everyday world. However, Mellor (1993) considers death in contemporary society is 'sequestered' rather than integrated. He holds a view that present day responses to death and related issues are becoming increasingly privatised, individualised and absent from public space. He attributes such responses to features of high modernity identified by Giddens (1990, 1991), wherein individualism, reflexivity and skepticism prevail. Under such conditions, Mellor suggests, individuals construct and rely on their own meanings of living and dying.

Aspects of Mellor's perceptions of social attitudes to death are reflected in Walter's (1994) thesis of the contemporary nature of the dying experience. Walter claims that there appears to be a 'revival of death' in Western society and that death is re-entering the public sphere. He attributes this situation to an emerging language which gives voice to the private feelings and responses of dying persons and their loved ones. In addition, he suggests, dying persons are making individual decisions regarding their approach to the dying experience. Walter proposes a typology of cultural responses to death as a basis for interpreting and understanding dying and bereavement. He describes three forms of death: *traditional*, *modern* and *neo-modern*, differentiated on a thematic framework including contexts, authority, coping, the journey, and, values (Walter 1994, pp.48-60).

Traditional death, Walter suggests, is typified by the death of young persons, commonly occurring as the outcome of major infectious diseases or on the other hand, by individuals who survive to old age. Persons both young and old live as members of a social and functional community and death is a 'public' event. The dying process is short; respect for the dying person and for traditional practices are of paramount value.

Essentially, dying is a journey of the soul. Support is provided to the dying person by family members, neighbours and clergy, and through established rituals known to all. The image of the good death is the opportunity to farewell family and to prepare for life after death. The bad death is perceived as one for which dying persons are unprepared, unbelieving and denying their God.

Heart disease or cancer are identified by Walter as common causes of the *modern form of death*. Typically, death is that of an adult person. The dying pathway in the modern form of death is hidden; privacy and dignity are valued. Essentially, dying is a journey of the body. Authority is vested in medical expertise and the dying person is supported through technology and medications and members of the immediate family. The good death is one where dying is painless and quick. The bad death is seen when the dying person lacks the will to live and exhibits dependency on others.

Walter suggests that common causes of the *neo-modern form* of death are cancer and AIDS. Death is typically that of an older person. The dying process is 'prolonged' and although the dying person interacts with others, the person's moment of death is a private event. Choice and autonomy are valued and authority lies with the person who is dying. Essentially, the dying journey extends deeply within the self. Support is provided by communities of counsellors and self-help groups and through selected rituals. The good death is one where persons are aware of death, have followed their own idiosyncratic pathways during the dying process, and

psychological closure of all personal matters has occurred. The image of the bad death is seen as isolation from others and 'psychological denial'.

Walter's constructions of dying as outlined above, are theorised, in the main, in the context of Western society and English-speaking communities, in particular.

While providing a cogent representation of aspects of the dying experience, the various forms of death are essentially abstractions. In a multicultural society, such as Australia, it is argued there is diversity in beliefs and understandings of mortality and immortality and in faith traditions, mores, language use and the social practices associated with death and the dying experience (Taylor and Box 1999; Prior 1999; Kanitsaki 1998).

Essentially, meanings of illness, dying, death, and, afterlife, are unique, individual and personal. They can change as we live our lives. Confrontation with impending death requires that we give 'final meaning' to the phenomena of life and death (Janssens et al 1999). In such circumstances, many people explore more deeply their understandings of God or their faith traditions. Some persons seek to 'befriend death' (Nouwen, 1982, p.189) and to experience dying as potential opportunity for personal growth and spiritual transcendence or as a pathway, ultimately, to dwelling in love with the 'Eternal', the 'Divine'. Others may perceive dying as transition towards rebirth or transition towards meaninglessness and annihilation. Tillich (1952, p.42) claims that the threat of non-being, which follows confrontation with the reality of one's mortality, generates 'inescapable' anxiety. The actuality of dying may not only threaten, sometimes it may overwhelm the integrity of the person, who can experience a life-world that is chaotic and 'out of control' (Turley 1988, p.60).

The diversity and complexity of responses to phenomena of death and dying shape the nature of care appropriate to dying persons in their wholeness and to their families. Awareness of and sensitivity towards the plurality of spiritual and cultural values and customs among Australian communities is required of all persons involved in patient/family care services. For the purposes of this paper, care of dying persons relates to care of persons of non-indigenous communities and to specialist palliative care services only.

Approaches to palliative care and service delivery

Modern approaches to palliative care were developed in England during the 1970s under the leadership of Dame Cicely Saunders. Saunders' philosophy of care (Saunders and Baines 1989) has been adopted in some form by many countries throughout the world, including Australia. As a concept, hospice/palliative care encompasses holistic care of patients who are terminally ill and support for patients' families. In collaboration with patient and/or family, as culturally appropriate, interdisciplinary teams of health professionals and others, plan, provide and evaluate care.

Activities of the care team are directed towards prevention and treatment of a patient's disease symptoms and to addressing issues raised by patient and family as changes occur in life style and in meanings and understandings of the patient's living/dying journey.

Services are commonly offered in a range of settings: hospices, hospitals, private homes, day care centres, and, nursing homes. They are delivered, where possible, in the environment of the person's choice.

Since Saunders' pioneering work at St Christopher's Hospice, changes have occurred and continue to occur in palliative care practice and its emphases and palliative care as a concept continues to evolve (Aranda 1998; Corner and Dunlop 1997; Neale 1993; Small 1993). For instance, present day palliative care is seen to extend beyond the care of patients in the final stages of life to include also care of persons at an earlier stage of irreversible illness, although for some people with AIDS, the end-stage of the disease may not be readily identified (Nicholson, 2000).

Continuing development of new drugs and other technologies can result in episodes of disease quiescence and, in some situations, temporary cessation of palliative care services may follow. In addition, multiple understandings of the nature of death and dying, differing systems of care management across service settings and integration of most palliative care programs within mainstream health care bring with them changes in understandings of effectiveness, efficiency and outcomes of care programs and associated practices.

Where appropriate and available, volunteers may be involved in care programs in any setting where services are delivered. Activities of volunteers are complementary to those delivered by the palliative care team and do not replace or reduce services offered by health professionals and others. As 'non-professional' members of the care team, volunteers with their diverse cultural backgrounds, life experiences and occupational skills, may bring a 'fresh attitude and outlook' and way of thinking to that shared by other groups within the healing community (Buckingham 1983, p.46).

Volunteers and the nature of volunteering

Broadly defined, volunteering is an activity in which individuals of their own free will choose to provide services to a community without financial return. Formal volunteer groups commonly organise for purposes of self help, to provide services or to address social change through civic/community development. Informal volunteering refers to those activities which are performed casually outside the family, to friends, neighbours, and others. In this paper, formal volunteering only is addressed.

Profiles of volunteers in the general community

In Australia, almost one of every five persons over the age of 15 years (19% of the population) participate in

some kind of formal volunteering in any one year, the rate being highest in the 34-45 year age group (Australian Bureau of Statistics (ABS) 1996, p.1). Persons in all States and Territories who live in capital cities are less likely to volunteer than persons who live outside capital cities.

Gender and age differences are evident in relation to several aspects of volunteering rates, areas of activity and the nature of tasks undertaken (ABS 1996). For instance, the ratio of females who participate in voluntary work is higher than that of males (21.3% compared with 16.6%), the higher rate for women being consistent throughout all States and Territories (ABS 1996, p.1). A large proportion of female volunteers are involved in areas such as welfare/community and education (ABS 1996, p.4); in areas of welfare/community the rate steadily increases until 64 years of age (ABS 1996, p.2). In contrast, a large proportion of male volunteers tend to participate in the area of sport, hobby and recreation (p.4), the rate in that area decreasing after 45 years of age.

The reasons people give as to why they volunteer vary widely. In the main, statements cluster around a desire to help people, gain personal satisfaction, engage in social interaction, learn new skills, and, gain work experience (ABS 1996; Noble 1991; Vellekoop-Baldock 1990).

Metaphors of volunteering

Within discourses of volunteering, there are various metaphors which seek to portray aspects of the phenomenon and values associated with it. These metaphors include notions of volunteering as a 'gift' to 'strangers' (Titmuss 1970); a form of social capital (Onyx and Leonard, 2000; Noble 2000); and, 'a caring and compassionate practice' (Wuthnow 1991).

During the 1960s, Titmuss (1970) examined the giving, receiving and payment of supplies of human blood for distribution through blood transfusion services in Britain, the USA and elsewhere. Titmuss (1970) described the giving and receiving of blood in Britain as 'a gift' by individuals to 'strangers' - a freely chosen, non-economic act offered without obligation, right or wish for return. This was not to claim however, that the gift transaction was without reciprocity; it might comprise elements of self-interest as well as generosity and kindness. In the USA, by contrast, blood was considered a product for market consumption and the giving of blood an economic transaction.

Sets of circumstances similar to the giving and receiving of blood within the blood transfusion system in Britain are seen to relate to other community services involving volunteer participation. In selected areas of social life, individuals freely choose to engage in activities of various voluntary organisations, giving their time, skills and experiences without obligation or wish for return, in order to further 'the common good' or to enhance the

well-being of persons or groups, who are strangers to them (in most instances).

Social capital, according to Cox (1995, p.11), is 'a collective term for the ties that bind us'. In a similar vein, Putman (2000, p.19) describes social capital as 'connections among individuals - social networks and the norms of reciprocity and trustworthiness that arise from them'. The establishment of social networks through volunteering offers opportunity for establishing and strengthening social cohesion, integration and interdependence among persons and groups with differing interests, skills, concerns, institutional and occupational experiences.

Participation of volunteers in palliative care services, for example, requires volunteers to develop co-operative relationships with peers, members of professional and administrative groups within health care, patients, family members and others. Interpersonal relationships within patient/family care programs are founded on trust and respect for the integrity of the individual; such relationships are covenantal. The networks created through social linkages between professional carers, non-professional carers and patients and families offer potentially rich media for enhancing the social wealth of the care team and extending to the wider community also.

Subsequent to his study of volunteering in the USA, Wuthnow (1991) concluded that, while upholding values of individualism, freedom and self-interest, paradoxically, Americans are committed to caring and giving also. To explain this situation, Wuthnow suggests that volunteering is a means by which citizens express care and compassion. Volunteering, Wuthnow (1991, p.266) claims, is a 'way of envisioning a better society'.

The word compassion is derived from the Latin *com* - with and *pati* - to suffer and is defined as: 'sympathetic consciousness of others' distress together with a desire to alleviate it' (Longman Dictionary 1991).

From a philosophical perspective, Nussbaum (1996, p.28) claims, compassion 'is a central bridge between the individual and the community; it is conceived of as our species' way of hooking the interests of others to our own personal goods'.

Preparation of volunteers for participation in contemporary palliative care

The vulnerability of patients admitted to palliative care programs and the potentially stressful nature of the volunteer experience necessitate establishment of formal management systems to assess suitability of applicants to the volunteer role. Individual agencies determine selection criteria, screening procedures, appointment processes and induction programs appropriate to the responsibilities of volunteers and the services they offer (Palliative Care Australia 1999). To ensure information transfer and

ongoing appraisal of care activities, clear channels of communication between volunteers and members of the interdisciplinary health team are required. Although processes of communication vary among palliative care agencies, it is usual for volunteers to communicate directly or indirectly with nursing personnel or with client support workers. In some instances, volunteers may communicate directly with the care team manager, who, frequently, is a nurse.

Subsequent to involvement in care services, volunteer monitoring and support processes and continuing education programs are entrained.

Volunteers in palliative care services

The role of the palliative care volunteer is 'to strengthen' and support the abilities of patients and their carers 'to live as fully and as richly as possible' during the varying phases of the illness experience (Palliative Care Australia, not dated). Examples of activities commonly performed by volunteers may include: providing transport and company for patients to and from out-patient clinics and day care centres; participating in day care centre programs; visiting, on a regular basis, 'house-bound' patients who live alone; providing opportunity of respite, on a regular basis, to a family member, who may be a sole lay carer; providing support to patients admitted to in-patient hospice/palliative care services and to family members; and, participating in bereavement 'follow-up' and remembrance services.

As disease progresses, patients may experience changes in body image, fluctuations in energy levels, changes in functional capacities and social roles, and, increasing dependency. Unable to continue regular employment or recreational activities, or to venture far from home, patients can experience loneliness, vulnerability and social isolation.

Interaction with volunteers in a non-threatening relationship provides opportunity for patients to remain engaged in a wider world and to shape and define their life-world. For those patients living alone, regular visitation by a volunteer provides opportunity for participation in activities of interest to them and which are within their capabilities. Volunteer anecdotes commonly instance activities such as: a leisurely walk to the post box to mail a letter or to exercise an aged terrier; quiet conversation; a game of cards; watching/listening to and discussing favourite television programs, music or sport; and, accompanying a person on a visit to the dentist or optician.

Like patients, family carers may become socially isolated also. In addition, they may become fatigued and stressed by the burden of care and the impending death of their loved one. Studies of the effects of home care on lay carers, usually family members or friends, (Payne et al 1999; Grande et al 1997; Hinton 1996), suggest that lay carers be viewed as 'co-clients', who require needs

assessment separate from that required by patients. Findings from such studies also indicate that the kind of support appropriate to carers may differ from that offered to patients. Opportunity for lay carers to share time and space with friends, neighbours or their own selves, outside the home, can enhance coping strategies and contribute to improvement in the quality of life of both carers and patients. In addition to institutional respite services, volunteers can provide regular intervals of respite for lay carers at different stages of a patient's illness experience, including end-of-life stage.

Aware of and responsive to the diverse and changing needs of individual patients and families during the illness experience, palliative care nurses are deeply involved in planning and evaluating with the patient/family and other members of the health team, the delivery of comprehensive care services - including the appropriateness or otherwise of volunteer involvement in patient/family care.

Trust and respect for the integrity of the other allows professional relationships between nurses and volunteers and between volunteers and other health workers to develop and strengthen. Shared understandings and open communication among individuals as members of the interdisciplinary care team are seen to facilitate the provision of coordinated and sensitive services and achievement of care goals.

In their activities with patients and families, volunteers offer time, presence and a part of themselves to others, as 'strangers'. Presence, in this sense, connotes *being there* and *being with* (Gilje 1992, p.56). *Being there* and *being with* may require dwelling in companionship and friendship with the other in their silence and in their moments of anguish, anxiety and uncertainty or sharing their laughter or their unexpected joy. Presence invites connecting more deeply with patient and family members and their meanings of suffering, living and dying. Being present requires the volunteer to listen attentively to patient and family members as they reminisce about significant and less significant events in their life stories, or ponder aloud, with feelings of anger or acceptance, what tomorrow might bring and how things might be for them and to respond appropriately.

Being present to persons who are suffering, is demanding emotionally. Caring for and caring about dying patients and their loved ones require that volunteers (like nurses and other members of the palliative care team), learn to cope with and manage, in thoughtful and sensitive ways, the many and varied emotions surrounding the reality and meanings of death and of dying experienced by the individual patient and family members. As James (1992, 1989) points out, in some situations, the emotions one feels may not be what one expects to feel or 'should' feel. Handling complex emotional responses requires energy and effort and is considered by some researchers

(Staden 1998; Bolton 2001, 2000) as a form of work - 'emotion work'.

'Emotion work' is a term coined by Hochschild (1979, p.560) to describe 'the act of trying to change in degree or quality an emotion or feeling' so as to convey to others those emotions deemed 'appropriate' to a situation. Hochschild (1983) considers 'emotion work' requires something extra on the part of the worker whereby a part of the self is offered as a gift to another. The 'emotion work' of members of the palliative care team, both professional and 'non-professional' is seen to offer a distinctive contribution to the quality of care delivery.

CONCLUSION

Volunteering in the context of palliative care is an expression of a person's choice of involvement in caring about and commitment to the welfare of others. Volunteer participation in care delivery broadens the range of services hospice/palliative care agencies can offer and contributes to the quality of life of patients and families. The sets of relationships created between volunteers and professionals with specialised knowledge and skills in caring for dying patients and between volunteers and patients/families facilitate awareness among disparate community groups of services available to dying and bereaved persons. Such relationships also provide a medium for interchange of understandings and expectations about care of dying persons and bereaved others, for death is an event which is both private and public.

Reports in the nursing literature of studies of volunteer participation in the delivery of palliative care in Australia are few. Given the continuing development of palliative care services, it would seem appropriate in terms of future planning, that comprehensive studies of the role, functions and experiences of volunteers in both community and institutional settings be undertaken and that volunteer inclusion in care programs be evaluated.

REFERENCES

- Aranda, S. 1998. Palliative care principles: Masking the complexity of practice. In Parker, J and Aranda, S. (eds.). *Palliative care explorations and challenges*. Sydney: MacLennan and Petty.
- Ariés, P. 1981. *The hour of our death*. Translated by Helen Weaver. London: Penguin.
- Australian Bureau of Statistics. 1996. *Voluntary work Australia June 1995*. Canberra: Australian Government Printing Service.
- Bauman, Z. 1992. *Mortality, immortality and other life strategies*. Cambridge: Polity Press.
- Bolton, S. 'A' 2001. Changing faces: Nurses as emotional jugglers. *Sociology of Health & Illness*. 23(1):85-100.
- Bolton, S. 'B' 2000. Who cares? Offering emotion work as a 'gift' in the nursing labour process. *Journal of Advanced Nursing*. 32(3):580-586.
- Buckingham, R.W. 1983. *The complete hospice guide*. New York: Harper & Row.
- Bury, M. 1997. *Health and illness in a changing society*. London: Routledge.
- Comer, J. and Dunlop, R. 1997. New approaches to care. In Clark, D., Hockley, J. and Ahmedzai, S. (eds.). *New themes in palliative care*. Buckingham: Open University Press.

- Cox, E. 1995. *A truly civil society*. 1995 Boyer Lectures. Sydney: Australian Broadcasting Commission.
- Elsay, B. 1998. Hospice and palliative care as a new social movement: A case illustration from South Australia. *Journal of Palliative Care*. 14(4):38-46.
- Giddens, A. 'A' 1991. *Modernity and self-identity: Self and society in the modern age*. Cambridge: Blackwell.
- Giddens, A. 'B' 1990. *The consequences of modernity*. Cambridge: Polity.
- Gilje, F. 1992. Being there: An analysis of the concept of presence, in Gaut, D.A. (ed.). *The presence of caring in nursing*. New York: National League for Nursing. Pub.No.15-2465.
- Grande, G.E., Todd, C.J. and Barclay, S.I.G. 1997. Support needs in the last year of life: Patient and carer dilemmas. *Palliative Medicine*. 11:202-208.
- Hinton, J. 1996. Services given and help perceived during home care for terminal cancer. *Palliative Medicine*. 10:125-134.
- Hochschild, A. 'A' 1979. Emotion work, feeling rules and social structure. *American Journal of Sociology*. 85(3):551-575.
- Hochschild, A. 'B' 1983. *The managed heart: Commercialization of human feeling*. Berkeley: University of California Press.
- James, N. 'A' 1992. Care = organization + physical labour + emotional labour. *Sociology of Health & Illness*. 14(4):488-509.
- James, N. 'B' 1989. Emotional labour: Skills and work in the social regulation of feelings. *Sociological Review*. 37:15-42.
- Janssens, R.M.J.P.A., Zylicz, Z. and Ten Have, H.A.M.J. 1999. Articulating the concept of palliative care: Philosophical and theological perspectives. *Journal of Palliative Care*. 15(2):38-44.
- Kanitsaki, O. 1998. Palliative care and cultural diversity, in, Parker, J. and Aranda, S. (eds) *Palliative care: Explorations and challenges*. Sydney: MacLennan & Petty.
- Kasap and Associates 1997. Report to the Palliative Care Program Review. Steering Committee 1996. Stage One. Canberra: Australian Government Printing Service.
- Kingsbury, K. 1980. *I want to die at home*. Revised Edition. Heidelberg: Fraser and Jenkinson.
- Longman Dictionary of the English language. New edition. 1991. Essex: Longman Group UK.
- Mellor, P.A. 1993. Death in high modernity: The contemporary presence and absence of death. In Clark, D. (ed.). *The sociology of death: Theory, culture and practice*. Oxford: Blackwell.
- Neale, B. 1993. Informal care and community care. In Clarke, D. (ed.). *The future for palliative care: Issues of policy and procedure*. Buckingham: Open University Press.
- Nicholson, J. 2000. Can the development of palliative care services meet the needs of people with HIV? *Journal of Palliative Care*. 16(2):37-43.
- Noble, J. 'A' 1991. *Volunteering: a current perspective*. Adelaide: The Volunteer Centre of SA Inc.
- Noble, J. 'B' 2000. The future of volunteering. In Warburton, J. and Oppenheimer, M. Eds. *Volunteers and volunteering*. Leichhardt: The Federation Press.
- Nouwen, H.J.M. 1982. Befriending death. In Durbach, R. (ed.) 1998. *Seeds of hope: A Henri Nouwen reader*. (2nd ed). London: Darton, Longman and Todd.
- Nussbaum, M. 1996. Compassion: The basic social emotion. In Paul, E.F., Miller, F.D. Jr and Paul, J. (eds.). *The communitarian challenge to liberalism*. Cambridge: Cambridge University Press.
- Onyx, J. and Leonard, R. 2000. Women, volunteering and social capital. In Warburton, J. and Oppenheimer, M. (eds). *Volunteers and volunteering*. Leichhardt: The Federation Press.
- Palliative Care Australia. 'A' 1999. *Standards for palliative care provision*. (3rd Edn.) Yarralumla. ACT: Palliative Care Australia.
- Palliative Care Australia. 'B' Not dated. *Volunteers: An integral part of the palliative care team*. ACT: Palliative Care Australia.
- Payne, S., Smith, P. and Dean, S. 1999. Identifying the concerns of informal carers in palliative care. *Palliative Medicine*. 13:37-44.
- Prior, D. 1999. Culturally appropriate palliative care for Indigenous Australian people in Aranda, S. and O'Connor, M. (eds.) *Palliative care nursing: A guide to practice*. Ascot Vale: Ausmed Publications.
- Putman, R. 2000. *Bowling alone: The collapse and revival of American community*. New York: Simon & Schuster.

Redpath, R. 1998. Palliative care in Australia. In Ramadge, J. (ed.) *Australian nursing practice and palliative care*. Deakin, ACT: Royal College of Nursing Australia.

Saunders, C. and Baines, M. 1989. *Living with dying: The management of terminal disease*. 2nd edn. Oxford: Oxford University Press.

Small, N. 1993. HIV/AIDS: Lessons for policy and practice in Clark, D. (ed.). *The future for palliative care: Issues of policy and procedure*. Buckingham: Open University Press.

Staden, H. 1998. Alertness to the needs of others: A study of the emotional labour of caring. *Journal of Advanced Nursing*. 27:147-156.

Stoddard, S. 1992. *The hospice movement: A better way of caring for the dying*. (Revised edition) New York: Vintage Books.

Taylor, A. and Box, M. 1999. *Multicultural palliative care guidelines*. Yarralumla, ACT: Palliative Care Australia.

Tillich, P. 1952. *The courage to be*. New Haven: Yale University Press.

Titmuss, R.M. 1970. *The gift relationship: From human blood to social policy*. London: Allen & Unwin.

Turley, A. 1988. Needs of the dying in Gardner, H. and Aroni, R. (eds.) 1988. *Dying with dignity: Ethical, religious and cultural perspectives*. Centre for Applied Social Research in Health, Multi-Faith Resource Centre. National Association for Loss and Grief. Victoria.

Vellekoop-Baldock, C. 1990. *Volunteers in welfare*. Sydney: Allen & Unwin.

Walter, T. 1994. *The revival of death*. London: Routledge.

Wuthnow, R. 1991. *Acts of compassion: Caring for others and helping ourselves*. Princeton. New Jersey: Princeton University Press.

RESEARCH ROUNDUP A summary of research reports from nursing and medical journals

DEMENTIA RISK REDUCED BY LEISURE ACTIVITIES

New research shows individuals who engage in leisure activities, such as reading, visiting friends and watching films at the cinema significantly reduces their risk of developing dementia. A seven-year study of more than 1700 New York residents, aged 65 years or over, compared the residents' leisure activities using standard annual physical and neurological examinations. The results showed that while 207 individuals developed dementia during the study period, the relative risk of dementia decreased in those with highly developed leisure activities. The study authors suggest engagement in leisure activities may reduce the risk of dementia by providing a reserve that delays the onset of clinical manifestations of the disease process.

Reference

Scarmeas, N., Levy, G., Tang, M.X., Manly, J. and Stern, Y. 2001. *Influence of leisure activity on the incidence of Alzheimer's Disease*, *Neurology*, 57:(12):2236-2242.

EFFECTS OF SHIFT WORK ON THE METABOLISM

Swedish researchers have tested the effects of shift work on obesity and other health problems in a sample of almost 28,000 Swedish workers. They compared shift workers with day workers on measures of cholesterol, triglycerides, overweight and blood sugar. They found that obesity was prevalent among the shift workers. Also, shift workers in various age and sex groupings had higher levels of other risks which contribute to what is known as 'the metabolic syndrome', or 'syndrome X'. Syndrome X is a combination of risk factors that appear to occur together. Initially four risks - elevated BP, high cholesterol, high blood sugar and abdominal fatness - made up the syndrome. More recently, other factors such as increased blood clotting factors, smoking and inactivity have been included. This cluster of risk factors usually leads to more serious disease, such as diabetes, heart disease, gallstones, polycystic ovaries and some cancers. Shift workers in the Swedish sample were shown to have a much higher risk of all these factors than daytime workers. Women shift workers appeared to fare worst. As well as an increased risk of obesity, their risk of having three metabolic risk factors (triglycerides, LDL and HDL cholesterol) was 70% higher than day workers.

Reference

Karlsson, B., Knutsson, A. and Lindahl, B. 2001. Is there an association between shift work and having a metabolic syndrome? Results from a population study of 27,485 people. *Occupational and Environmental Medicine*, 58(11):747-52.

INDIGENOUS AUSTRALIANS LESS LIKELY TO HAVE DIAGNOSTIC TESTS

Australian patients identified as indigenous are less likely to have diagnostic tests and therapeutic procedures than other inpatients in Australia's public hospitals, according to a new study. Menzies School of Health Research Epidemiologist Dr Joan Cunningham examined National Hospital Morbidity Database data for acute treatment episodes between 1997-1998. This data included information on the characteristics, diagnoses and care of inpatients in almost all public and private hospitals in Australia (excluding the Australian Capital Territory) - with more than 4.8 million separations recorded. The study did not include statistics for renal dialysis separations. The study shows patients identified as indigenous were significantly less likely to have a procedure or test performed: 45% compared with 69% for other patients. The difference was even more marked for circulatory, digestive and genitourinary problems, where indigenous patients were only half as likely to undergo tests and procedures as other patients.

Reference

Cunningham, J. 2002. Diagnostic and therapeutic procedures among Australian hospital patients identified as indigenous. *Medical Journal of Australia*, 21 January, 176(2):58-62.

IV SETS SAFE AFTER SEVEN DAYS

Australian researchers have found that intravenous administration sets retain acceptable accuracy and condition after seven days of continuous use. The researchers stated that the duration of administration set use was unknown and that although studies have investigated infection control issues, none has considered the accuracy of volume delivery or integrity of administration sets after prolonged use. For the study, four administration sets were randomly assigned to deliver 2ml/hr (IMED syringe set 2280-0000), 20, 50 or 100ml/hr (IMED infusion sets 2210-0500) of crystalloid solution continuously for seven days. The researchers found small inaccuracies between programmed and delivered volumes, but that there was no deterioration in performance over time. The authors suggest that the inaccuracies were because of the pump rather than the administration sets' performance.

Reference

Rickard, C., Wallis, S., Courtney, M., Lipman, J. and Daley, P. 2002. Intravascular administration sets are accurate and in appropriate condition after 7 days of continuous use: An *in vitro* study. *Journal of Advanced Nursing*, February, 37(4):330-337.